

Shared Living Guide

Robin Cooper, Kara LeBeau, and Nancy Thaler
NASDDDS

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Introduction

This guide to shared living is not about beds, slots, or facilities. It is about creating the opportunity for people with developmental disabilities to have a home and people to share everyday life with. It is about people living together in long-term relationships, sharing life's ups and downs together. It is about being a member of the community. This guide explains what shared living is, and provides advice on building a program – and the infrastructure necessary – to achieve these outcomes.

This guide is for state developmental disabilities (DD) agencies and for affiliated government entities responsible for designing and managing services. It will be useful to anyone responsible for developing services to support people who cannot, or who do not want to, live alone or in a residential facility. The ideas and information presented here come from the experience of state developmental disabilities agencies and provider organizations that have pioneered shared living. We have consciously chosen to profile a small number of states that have distinguished shared living from their other in-home and residential programs, fully recognizing that many states and provider organizations offer shared living opportunities as a part of their programs.

The states highlighted in this report have clearly identified shared living as distinct from other services and have put together supports, manuals, guidelines and materials specifically addressing shared living. In general, this guide focuses on supporting adults in shared living – but many of the same values, principles, and processes described may apply to serving children.

Structure

The guide is divided into four chapters, plus appendices and a resource list:

Chapter 1: Why this guide is Important to the Developmental Disabilities Field...

offers a look at national demographic and economic trends that are affecting states' ability to sustain current systems.

Chapter 2: What is Shared Living?... provides a definition and description of shared living as well as an explanation of the benefits. Person-centered thinking and self-determination as the foundation of shared living are also explained.

Chapter 3: How States Implement Shared Living... explains the service system components necessary to effectively develop and sustain shared living. This chapter will describe the roles and responsibilities of various state and sub-state entities; the types of training and support that are most effective for shared living providers; the kinds of standards and regulations states employ for shared living; and in considerable detail, payment methodologies and quality oversight. In addition, information is offered on the IRS tax rules that apply to some shared living arrangements.

Chapter 4: Identifying and Managing the Risks of Shared Living... describes the risks inherent in shared living and how to mitigate them.

Appendices and Resources... provides additional materials and a list of resources on shared living.

Sherrill came to the idea of sharing her life as the result of a nagging feeling – which started when she read in a church bulletin about a man who was deaf and in need of a home. When her pastor pulled her aside and asked her if she would be willing to help, she spoke with her children (she'd always wanted to demonstrate in a tangible way to them that, although they did not have much in way of material things, yet they should always be willing to help others), and then Sherrill agreed to Leslie moving into her home.

But Sherrill was not fully aware of Leslie's various diagnoses and life struggles... Leslie and his father had been the best of friends. They had their own special communication system and Leslie had relied on his father to translate, advocate and intervene for him. At the Pennsylvania School for the Deaf Leslie learned rudimentary reading and writing; through his school years he worked at a restaurant and graduated with a major in Commercial Foods. But after his father died, Leslie went to live with his aunt, who lacked the skills to communicate with or for Leslie; she confined him to the house. Leslie's frustration led to hostility and destructiveness; he was admitted to the hospital, then released to a halfway house for two years. He remained terribly unsettled and anguished; was given excessive medications – which he often spit out – and his hygiene habits took a nose-dive. He was put out of the halfway house and began a series of difficult respite stays; he was hospitalized twice – once after a desperate attempted overdose; and then he was temporarily institutionalized. When Sherrill and her children welcomed him into their home, Leslie was homeless in every sense of the word: he had no place to live, no capable family, and his own body and soul offered him no shelter from what life was doing to him.

From the start, Sherrill and her children took sign language classes to be able to communicate with Leslie. But this required time and major daily adjustments from Sherrill and her family. She also had to fend off calls from neighbors and business owners who were angry, fed-up, or simply confused about what Leslie was doing. Slowly, Sherrill came to understand how Leslie's past was influencing his present. Sherrill and her children tried hard to help Leslie to feel like a part of their family. Essentially, he went everywhere they went – to soccer and basketball games, school functions, family gatherings, dinners, and movies. Over time, Leslie started to trust his new family members and understand that he was safe, that his belongings were safe, and that he was a valued and respected member of the family – and his social skills, table manners, hygiene reappeared.

Sherrill's children are now grown, but over the past 15 years, Sherrill has stood by Leslie through quite a few medical problems: cancer, accumulated severe tooth decay and removal, double bypass surgery, surgery for a pacemaker, and asthma.

Since becoming a part of Sherrill's family, Leslie is a changed man. He no longer reacts in anxious, hostile, destructive ways. He fully cares for himself, taking medications is no longer a problem, and his reputation around his neighborhood is that of a very social and gentle man. He always has a smile on his face – and what a smile!

Today, when Sherrill recalls reading that bulletin, with tears in her eyes, she says, "I just cannot imagine life without Leslie."

from "Knots That Bind, The Pennsylvania Lifesharing Newsletter"

Chapter 1:

Why is This Guide Important to the Developmental Disabilities Field?

Background and National Trends

Shared living is in some ways an old idea – but, in other ways, a very new one. It has at its foundation the concept we know as foster care – an idea about caring for children that was imported to the colonies from England.¹ But shared living is more than foster care because it also has, as its primary intention, the building of life-long relationships – based on the foundation of person-centered thinking and self-determination.

Since the early 1970s the rights of people with disabilities – to get an education, to live and work in the community, and to have access to all public facilities – have been firmly established through landmark federal legislation. In 1981, amendments to the Social Security Act provided the financial support necessary to allow people with disabilities to enjoy these affirmed rights when federal Medicaid funds were made available for home and community-based services. People left state operated institutions in great numbers: the institutional census dropped from 194,650 in 1967 to 33,682 in 2009. And children and adults living in the community and waiting for services began to enroll in home and community-based services provided through the Medicaid home and community-based waiver services program.

From the 1970s through 2009, the U.S. was trying to make good on a series of public commitments:

- that all children with disabilities would grow up as part of a family while attending public school with non-disabled peers;
- that adults would live and work in the community and experience the dignity of full citizenship; and
- that the public service system would provide the services and supports to make this all possible for everyone.

Although the first decade of the home and community-based services (HCBS) waiver program only saw 35,682 individuals with intellectual and/or developmental disabilities (I/DD) enrolled in the program, by 1999 that number had increased to 261,788. And by 2009, more than 300,000 individuals with I/DD were receiving waiver services.² In the early days the most rapidly developing service was group homes. Created as an option for people leaving institutions, group homes were also assumed to be the preferred option for adults living at home with their families. Except for modest state funded family

¹ "History of Foster Care in the United States" (National Foster Parent Association), <http://www.nfpainc.org/content/?page=HISTORYOFFOSTERCARE>.

² K. Charlie Lakin, Sheryl Larson, Patricia Salmi, and Amanda Webster, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* (University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2010).

support programs, group homes were the only community-based living arrangement available for many years. Families were often assured that their son or daughter would move out of the family home when he or she became an adult just like their brothers and sisters – and move into a group home.

As waiting lists grew and lawsuits were filed, states began to understand that the promise of a group home for everyone might be difficult to keep. And now several economic and demographic trends – as well as consumer expectations and demands – are converging to challenge leaders in the field to search for new approaches; specifically:

- **the aging baby boom generation** is causing rapid growth in age-related entitlement programs including Social Security, Medicare and long-term care services that are stressing the federal budget;
- **the national debt** has grown rapidly over the past 10 years to \$14.3 trillion;³
- **the economic crisis of 2009-2010**, with high rates of unemployment and significant drops in state revenue, has required cuts in existing programs and severely limited expansion of services. This trend is expected to hold through 2011 – and possibly through 2012 – with states continuing to have significant revenue shortfalls;
- **work force shortages:** the growing demand for long-term care services will rapidly surpass the growth in the number of working age adults in the next two decades;
- **waiting lists:** at least 20 percent expansion of the current residential system would be necessary to address the demand;
- **the cost of residential services:** 24-hour supervision is the most expensive model of community services;
- **a growing consumer demand for choice and control over services** and for service models that support life in the community rather than a "service life" (see sidebar).

Service life refers to receiving services that focus on health, safety, and functional skills. Those things that are referred to as being important to the person (those things that make the person happy, content, fulfilled, satisfied, or comforted) are not a focus for the organization....**Community life** is not defined simply by being in the community but by having relationships. When there is a web of reciprocal relationships, where there are people who care about the person and are not paid and not family and are engaged in their lives, then people are connected to a community life. This does not mean that those people supported no longer have paid people in their lives. It simply means there are more people in your life *than only family members or paid supporters*.

Michael W. Smull,
Mary Lou Bourne, and
Helen Sanderson,
*"Best Practice, Expected Practice,
and the Challenge of Scale"*
(April 2010, p. 3-4)

³ National Debt Clock as of May 13, 2011, www.usdebtclock.org.

The first six of these trends compel state directors of developmental disabilities services to develop more cost effective models of services as an alternative to 24-hour staffed residential programs. And, just as important, is the last trend – the growing consumer demand for choice and control – which presses for the creation of more inclusive, more person-centered approaches that result in a satisfying everyday life for the person receiving support.

TREND 1:

The Impact of the Aging Baby Boom Generation on the Federal Budget

In the 1930s, when the Social Security Act was adopted, life expectancy in the United States for men was 58 years of age; for women it was 62. In contrast, men born in 2005 have a life expectancy of 77 years and women born that year can expect to live 82 years.⁴

Sherry is a 44-year old woman with Prader-Willi Syndrome (PWS) which causes chronic hunger and slow metabolism. Many people with PWS are not able to live in a family setting due to behavioral issues.

However, Rose was willing to give Sherry a chance. The first few years were very rocky and filled with crisis, but neither Sherry nor Rose gave up.

Now seven years later, the bond between these two women is special – like mother and daughter. Sherry has lost a significant amount of weight and her medical issues are under control.

Rose's dedication has given Sherry a second chance for things she never had....a chance for love and family.

from Massachusetts MENTOR

Life expectancy at birth in the early decades of the 20th century was low due mainly to high infant mortality. By the 1940s those who did make it to 21 years of age could expect to live to 65. But only 54 percent of boys and only 61 percent of girls could expect to reach the age of 21. The number of children that survive to adulthood has increased significantly – with 72 percent of men and 83 percent of women born in 1990 expected to live to 65.

But the most significant trend over the past 70 years is the birthrate itself. The term "Baby Boom" is frequently used to identify the massive increase in births following World War II – between 1946 and 1964. In 2010, this generation will be between the ages of 46 and 64. There are about 76 million "boomers" in the U.S., representing about 29 percent of the population. These

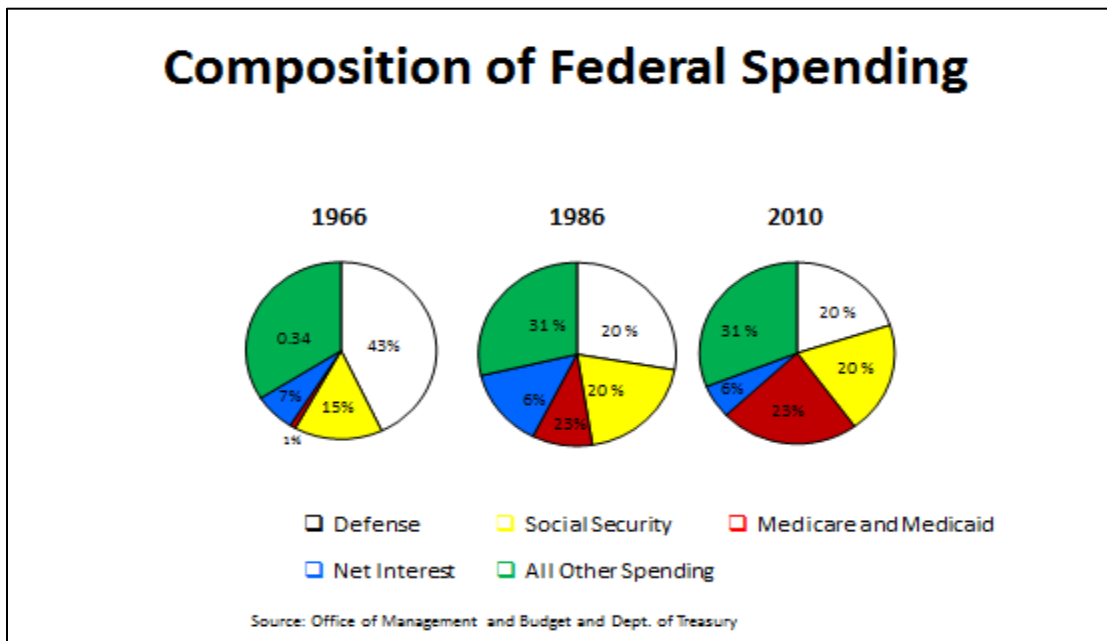
demographic factors are changing society – not only its composition, but in economic ways as well. The Social Security system is a "pay-as-you-go" system: not a savings or investment system, but a simple transfer from workers to retirees. The payroll taxes from each generation of workers are not saved or invested for that generation's retirement; rather they are used immediately to pay benefits for those already retired. The current generation of workers must then hope that when their retirement comes, the generation of workers following will pay the taxes to support their benefits, and so on.

⁴ "Life Expectancy for Social Security" (Social Security Online History), <http://www.ssa.gov/history/lifeexpect.html>.

Obviously, a pay-as-you-go system is very sensitive to the relationship between the number of people paying in and the number of people collecting benefits. In other words, the ratio of workers to retirees is crucial to the financing of the current system.

The current worker-to-retiree demographics in the United States spell trouble for Social Security's ability to keep up with its promised benefits. People are having smaller families, resulting in fewer new workers paying taxes into Social Security. And seniors are living longer and collecting benefits for many more years. And now the baby boom generation is about to retire.

But aging individuals will also participate in the Medicare program and a significant number will receive Medicaid long-term care services. All three programs are supported with federal funds (although in the case of Medicaid states provide up to a 50 percent). The following chart displays the growing impact of these age-related benefits on the federal budget over the decades – and it continues to grow.



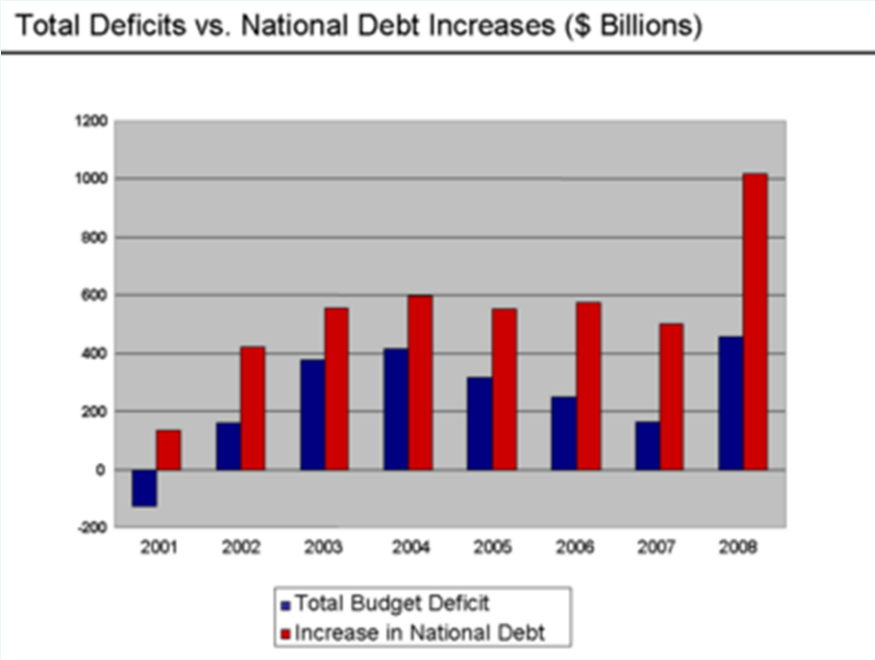
TREND 2:

The National Debt's Impact on the Availability of Federal Funding

Unfortunately, as demand for publicly funded services increases, the national debt is also growing. The United States government debt is the amount of money owed by the federal government of the United States to its creditors, whether they are nationals or foreigners. The debt has been increasing at a rate of more than \$500 billion each year since FY 2003, and as of January 2011, the total U.S. federal debt was well over \$13 trillion (see graph on following page).

While the lengthy wars in Iraq and Afghanistan, as well as a significant tax cut, increased the national debt, in reality it is long-term obligations and entitlements that place the most stress on the national budget. The Government Accountability Office (GAO), the Office of Management and Budget (OMB), the U.S. Treasury Department, and other budget watch groups have routinely warned that debt levels will increase dramatically if entitlement programs are not reformed. These organizations have stated that the government's current fiscal path is "unsustainable."⁵ Mandatory expenditures are projected to exceed federal tax revenues sometime between 2030 and 2040 if reforms are not undertaken.⁶ And the severity of the measures necessary to address this challenge increases the longer such changes are delayed.

The states, under pressure from long-term obligations, have come to rely on federal funding to support services to the elderly and to people with disabilities. Few states are in the financial position to support service expansion without federal financial participation.



Source: http://commons.wikimedia.org/wiki/File:Deficits_vs._Debt_Increases_-_2008.png

⁵ "The Federal Government's Financial Health: A Citizen's Guide to the 2008 Financial Report of the United States Government" (Government Accountability Office)
<http://www.gao.gov/financial/citizensguide2008.pdf>.

⁶ GAO Presentation – Slide 17 ^{a b} (2007 Report of the U.S. Government, p.47),
<http://www.gao.gov/financial/fy2007/07frusg.pdf>.

TREND 3:

The Economic Crisis of 2009-2010 (and 2011-2012)

The collapse of the housing market in the United States, followed quickly by a national banking crisis, has precipitated a global financial crisis that was just beginning to be understood in early 2009. The need for economic stimulus, remedies for the banking industry, and relief for home mortgage holders has added trillions to the national debt.

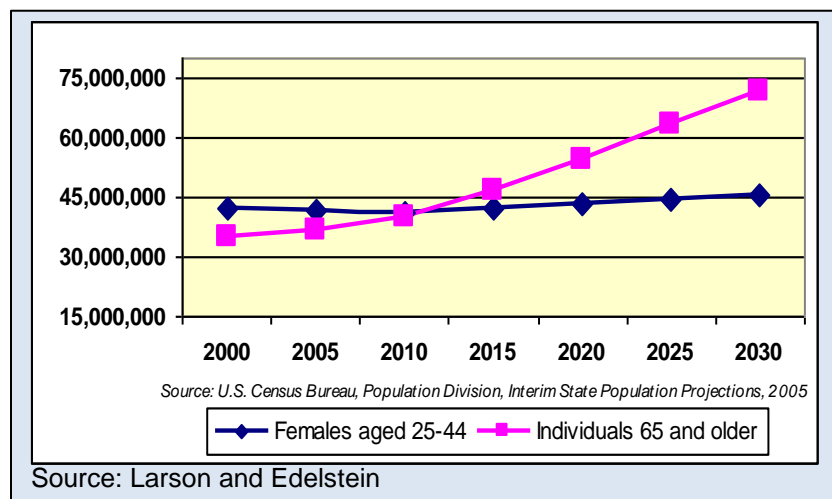
And the economic crisis has, of course, had an immediate impact on the provision of services to people with disabilities. Growing unemployment rates, home mortgage foreclosures leading to reduced purchasing – and consequent reduction in manufacturing and production – have led to reduced state revenues. With a severe shortage of revenue, states have been forced to reduce the number of government employees, cut provider rates, roll back services, and cancel plans for growth.

TREND 4:

Workforce Shortage

In the next two decades the growing demand for long-term care services will rapidly surpass the growth in the number of working age adults. This is yet another effect of the demographic shift in ages in our society. The growth of the baby boom generation is not matched by the rate of growth in the generation immediately behind the baby boomers, particularly

in the group that provides most care – females aged 25-44. The rate of growth among this population is relatively flat over time (see graph).



The "sandwich generation" is a term coined to describe working age adults who are caring for both their parents and their children at the same time – "sandwiched" between two generations that need their support and attention. As the baby boomers age, this phenomenon is likely to become more common. Baby boomers may not need long-term care services, but they may still need assistance in some aspects of daily life such as buying groceries, doing laundry, making meals, going to the doctor's office, etc. This will consume the time of working age adults – who might otherwise seek employment in long-term care services. The consequence of this demographic reality is that the ability to maintain 24-hour supervised living arrangements will become more and more challenging as the availability of working age adults becomes scarcer.

TREND 5: Waiting Lists Are a Reality in Most States

In a handful of states there are no – or at least very few – people waiting for services and, if there is a waiting list in these states, the wait for services is less than 180 days. But

In 2009, more than 99,870 people were waiting for services nationally.

Lakin, 2010

in most states, service expansion has not matched the level of need for many years and as the parents of people living with their families' age (the parents of baby boomers with developmental disabilities are now in their late 70s and 80s); states are faced with crisis after crisis.

According to the data reported in *Residential Services for People with Developmental Disabilities: Status and Trends Through 2009*, the estimated number of people in residential services was 439,515 in 2009, with more than 99,870 people on waiting lists.⁷ While waiting lists vary from state to state, on a national basis, the residential services system would have to grow by 20 percent to accommodate this demand. Shrinking state budgets and a shortage of direct care workers are insurmountable obstacles to the expansion of 24-hour staffed facilities.

TREND 6: The Cost of Residential Services

It has long been established that the cost of institutional services far exceeds the cost of home and community services. In 2009 the average annual costs of an ICF-I/DD⁸ per person were \$136,847 as compared to home and community-based services which cost \$45,463 per person.⁹ However, buried in the home and community services figures are residential services such as group homes. The cost of a group home for three individuals staffed around the clock can range from \$70,000 per person to \$100,000 depending on the level of staff attention needed.

In contrast, the cost of providing services to a person living with their family or with care-givers who provide both a home and support is more likely to range from \$15,000 to \$40,000. **Vermont** reported that the annual cost of group/staffed living arrangements in 2009 was \$89,740 per person, while shared living had an average annual per person expenditure of \$29,018.¹⁰ **Vermont** reports that part of what makes this a cost-effective

⁷ K. Charlie Lakin, Sheryl Larson, Patricia Salmi, and Amanda Webster, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* (University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2010).

⁸ We recognize that federal regulations still use the term ICF/MR but out of respect for self-advocates, we are using the term ICF-I/DD.

⁹ Lakin, et al., p.75.

¹⁰ "Shared Living in Vermont: Individualized Home Supports for People with Developmental Disabilities," (Vermont Division of Disability and Aging Services, Department of Disabilities, Aging, and Independent Living, 2010), p.6.

model is using the federal tax advantage provided under the "difficulty of care" option (see Chapter 3: Financing and Reimbursement).

TREND 7:

There is a Growing Consumer Demand for Choice and Control Over Services, Including Consumer-Directed Services

Melissa and her husband Scott and their young son Devon saw the potential in Dontae and decided that he should become a part of their family. And they have helped Dontae change his life dramatically.

Dontae, who had mild cognitive disabilities, cerebral palsy, and blindness, had been in and out of foster placements his entire life. At eight he was living in a Pennsylvania institution and had not been outdoors for over six months. Needing a feeding tube to eat any food other than Cheerios, he did not use the toilet; needed a walker to get around; and his behavior around most people was problematic and uncontrollable. It was commonly believed that he had little hope of speaking or of academic achievements

He now eats most foods and no longer uses the feeding tube. He has developed language – and has even learned to read some words. He no longer needs a walker; rides a horse; and feeds the chickens on the family farm. Most importantly, he now has a family that is committed to him and loves him as a brother and a son – and that has given him a chance to be the best that he can be.

**from "Knots That Bind,
The Pennsylvania Lifesharing Newsletter"**

More and more, individuals with developmental disabilities and their families want to have a more direct say in, and more control over, the services they receive. Dissatisfaction with traditional services is driving this demand for change. Group homes as well as sheltered workshops, the service models that have dominated the first generation of community services, are no longer acceptable – particularly to younger individuals and their families.

Service provided in congregate facilities, which isolate individuals from the community, is no longer the desired vision of individuals and their families.

Individuals who have grown up with their families, attended public schools, and are getting ready to take their place in the world want a typical life – living with people they like and who like and support them, working in a job, and being part of their communities.

And so – Why should state I/DD systems develop or expand shared living?

Most state service systems have a large component of residential services. In 2010, approximately 439,500 people received services in a residential facility (including ICFs-I/DD and other types of settings such as group homes) in the United States.¹¹ These facilities range in size, but over the years the populations of residential facilities has been dropping as states attempt to create more home-like settings. In 1996, only 53 percent of the people in residential settings lived with six or fewer people.¹² By 2009

¹¹ Lakin, et al., p.48.

¹² Lakin, et al.

that had risen to 73 percent – 321,463 people.¹³ This trend is positive. But there are several problems.

First, the waiting lists. As stated earlier, close to 100,000 people are waiting for services. Significant expansion of 24-hour staffed residential facilities to meet this demand is problematic – and perhaps even ill-advised – for several reasons, as also dealt with earlier: the financial pressures on states and the cost of 24-hour staffed facilities are substantial impediments to major expansion of 24-hour staffed residential services.

But beyond the financial limitations there is the frustration of trying to provide a real home for people when having to employ shift staff – who often have to work more than one job and who turn over rapidly. More than one administrator has expressed frustration with their inability to assure that people with disability will live a typical life in a home over which they have control. And certainly self-advocates share this same frustration. Wage and hour rules, nursing regulations, Medicaid requirements, and many other day-to-day realities combine to steal the "real life" from these living arrangements.

In many states, individual agencies offer shared living but there is no statewide commitment or guidance that specifically focuses on expanding true shared living. State systems must find new approaches that are financially and programmatically sustainable. In order to make a real everyday community life possible for people who rely on public systems to provide a home.

¹³ Lakin, et al.

Chapter 2:

What is Shared Living?

"Shared Living is exactly that: people sharing their lives by living together under the same roof as a family."

Rhode Island

Shared living describes an arrangement in which an individual, a couple or a family in the community share life's experiences with a person with a disability. The person who lives

with and provides companionship support to the person with a disability is typically referred to as the shared living provider. Other terms that can encompass the shared living approach include mentor, host family or family home, foster care or family care, supported living, paid roommate, housemate, and life sharing. As **Rhode Island's** description notes: "The shared living provider lives with the person and provides whatever support the person needs in their day-to-day activities. A shared living arrangement is usually in the shared living provider's home/apartment, but it could also be in the individual's home/apartment too. It may be a couple, a single person, or a family."¹⁴

The term "provider" here is used specifically to refer to the people who open their homes and their lives to an individual with disabilities and are compensated for doing so. There also are shared living arrangements where the individual providing support is NOT compensated or may receive other benefits such as free rent, which would not be considered "compensation" for services provided. This guide focuses mainly on compensated services but does not in any way preclude supporting the development of uncompensated arrangements. And some of the same concepts of making a match and supporting shared living may be useful in developing uncompensated situations as well.

Individuals supported in shared living include children and adults with a wide-variety of needs and challenges. One of the key tenets of shared living is articulated by a **New York** state consortium of agencies: "Everybody is ready. There are no criteria to receive the support...Since what occurs is individually designed, there are no prerequisites."¹⁵

People who choose to share a life with someone with a disability are of all ages, genders, races, nationalities, and religions. They are single people, college students,

"People select their lifesharers, no one is placed."

Dana Olsen
Pennsylvania ODP

¹⁴ Rhode Island's description of shared living found at www.mhrh.state.ri.us/about/pdf/sharedLiving.pdf.

¹⁵ "Creating Innovative, Individualized Living Options for Persons with Developmental Disabilities; It's not about a model; it's about an approach," (New York State Association of Community and Residential Agencies, Prepared for: New York State Developmental Disabilities Planning Council, December 2009), p.14.

single parents, empty nesters, and two-parent families with children. They may or may not work outside the home. Most people with disabilities in shared living arrangements work, volunteer, or are involved in the daily life of their community in some way. There are many different arrangements that can be developed based on individual and provider interests and preferences. Generally, states limit the number of people with disabilities in shared living arrangements to a maximum of two. And some states permit two individuals only when they are related or have a long-standing relationship and wish not to be separated.

Rhode Island offers some examples of shared living arrangements:¹⁶

- Ralph is a 63-year-old man who lives with Tom, a 65-year old retired widower on a farm. They both love to play golf and fish.
- Ellen, a 35-year-old woman with a full-time job, lives in the home of Frank and Betty, who have 4-year-old twins and who are very active in many of their community's events.
- Jim, a 48-year-old man, lives with a married couple: the wife still works but the husband is retired with lots of spare time. Jim has a part-time job.
- Susie is a 10-year-old-girl with a degenerative illness who lives with a couple who have three children ages 2 to 15. Susie has become "one of the kids."
- Lynne, a 27-year-old woman leaving home for the first time, shares her apartment with Sarah, a 28-year-old single professional.
- Pam and Tony, a young married couple, live in an in-law apartment in the home of Betty and Fred who are empty nesters.

The purpose of shared living is to enrich the lives of people with disabilities by matching those who choose this lifestyle with a family or an individual who choose to share a home and open their hearts.

Shared living offers an individual with a disability the opportunity to live with a family or an individual

who will support them and join with them to sustain their desires and wishes. Shared living offers the opportunity for both a close personal relationship and a place to live.

Shared Living is having a place where you belong and people who care about you – a home.

Pennsylvania

Why Is It Called Shared Living?

A name can communicate both vision and expectation. The term shared living emphasizes the vision that people will live together and share experiences. It communicates mutuality: A real *community life*, not a *service life*, is the expectation.¹⁷

¹⁶ Rhode Island's description of shared living is found at http://www.dhs.ri.gov/Portals/0/Uploads/Documents/Public/LTC/SL_fact_sheet.pdf.

¹⁷ See Michael W. Smull, Mary Lou Bourne & Helen Sanderson, "Best Practice, Expected Practice, and the Challenge of Scale," (April 2010), p.3-4.

The term shared living invites people to have an experience – rather than to work at a job or provide a service. And "share" means just that – not allow, permit, provide – but, as the Thesaurus offers, to "communicate, disclose, let somebody in on." This concept of sharing presupposes a *mutual* experience not a *hierarchical* one. Shared living presupposes mutual respect.

What Shared Living is Not

Shared living is not a place. It is not a "facility," or a group home. It is not traditional foster care or a bed in a boarding home. Shared living is not a supported "setting" serving three or four individuals with multiple "come-in" staff. It is important to understand what shared living is not because many of the practices and routines built into our system to manage residential facilities make no sense to citizens living in their own homes. We run the risk of undermining the core features of shared living if we do not appreciate the difference.

The **New York** State Association of Community and Residential Agencies (NYSACRA) has published an excellent monograph on individualized living options for people with intellectual disabilities, including supported and shared living, based on the formal input and efforts of professionals, providers, consumers, and families.

A graphic about supported living also describes shared living. Shared living is not:

- A program to fix and change people
- A curriculum or list of skills to remediate deficiencies
- Being grouped on the basis of disability
- Forcing people to live in a way we think is good for them
- Justified because it is always or necessarily cheaper than group living
- A way to avoid responsibility for careful decisions about threats to people's vulnerabilities
- Being assigned roommates
- A fixed amount of assistance forever¹⁸

Health, safety, and quality are as important in shared living as they are in any arrangement – but in shared living relationships and commitment, rather than rules and licenses, play a much stronger role in meeting these expectations. Shared living requires a new and different approach in recruitment and training, in assessing and managing risk, in record keeping, in monitoring and, most importantly, in the type and amount of support afforded to the shared living provider.¹⁹

¹⁸ "Creating Innovative, Individualized Living Options For Persons with Developmental Disabilities: It's not about a model; it's about an approach," (New York State Association of Community and Residential Agencies, Prepared for New York State Developmental Disabilities Planning Council, December 2009).

¹⁹ In New York, shared living typically refers to a situation where individuals are not compensated, but provide support. New York uses supported living as the term that indicates paid supports from a provider. New York uses the term "life sharer" when referring to shared living arrangements.

What are the critical components of shared living? What makes it work?

Commitment and Leadership. For shared living to be a viable alternative, the DD agency must first make an affirmative commitment to promoting and supporting shared living. This can be done through developing a specific service definition and attractive payment rates, through reworking rules to make them more flexible – and by developing specific plans to enhance the options for shared living. It is not just "rebranding" an old model – it is actively promoting changes in the ways we think about, and support, individuals with disabilities.

As early as 1988, the **Pennsylvania** Office of Mental Retardation (now Office of Developmental Programs) created a subcommittee on lifesharing. Lifesharing was defined as "... living with and sharing life experiences with supportive persons who form a caring household. Lifesharing is recognizable as being both a close personal relationship and a place to live."

Pennsylvania allowed lifesharing in licensed homes for up to two individuals and unlicensed settings for one person under its regulations. Although lifesharing was already permissible, Pennsylvania was invested in promoting this option. Beginning in 2005, Pennsylvania enhanced its efforts to develop more opportunities for shared living. Counties were required to develop a strategic plan to expand shared living that included current and potential providers as well as individuals and families. Pennsylvania went on to describe the expected plan in a bulletin:

"The strategic plan for Lifesharing is expected to ensure that:

- Individuals and their families are informed of the benefits and have the opportunity to choose Lifesharing when they apply for out-of-home residential services, including individuals who are exiting the school system and/or Early Periodic Screening, Diagnosis and Treatment (EPSDT), and individuals who need mental health supports and services.
- Individuals in residential services and their families are informed of the benefits and have an opportunity to choose Lifesharing during the individual's annual plan review.
- Supports coordinators receive training and technical assistance on how Lifesharing is provided.
- Individuals and their families have choice of the provider agency and Lifesharing family or companion.
- Interested county and support coordination staff are supported and encouraged to participate in state lifesharing subcommittee meetings, training, and regional gatherings.
- Information on lifesharing is shared at agency, county and regional events such as conferences and provider fairs, family conferences and media opportunities such as newspaper articles, TV ads, radio spots and websites.

- Information, including this bulletin, is shared with self-advocates, birth families, Lifesharing families and companions."²⁰

Maine is making a conscious effort to establish shared living as distinct from other existing programs, and has amended its HCBS waiver definitions to reflect shared living as a stand-alone service – separate from other programs and services that support people in their own or their family's home.

In 2010, **Rhode Island** announced a program of incentives to attract providers to offer shared living opportunities, and kicked it off with the governor's announcement that shared living is "an important alternative to group homes since in the last analysis those who participate seem to thrive and the cost is half of that of a group home placement." Under the incentive program, the state shares half the saving realized through a shared living placement with the agencies involved in moving the individual. (This is discussed in more detail in a later section.)

Offering incentives and including shared living as a formal requirement in strategic planning are affirmative and critical steps to expanding shared living.

Matching means a harmonizing of values, interests, and mutual commitments.

Pennsylvania

The Match. The second most essential component of shared living is the "match." As **Pennsylvania** notes in their bulletin on shared living, "The success of shared living rests on the thoughtful and careful

process of introducing people to each other and assuring the relationships work. The Pennsylvania bulletin referenced above emphasizes that the match process takes time: "In order to make a successful match, three to six months start-up funding is needed to facilitate the development of relationships and place a person in the county where they want to live."

This match is mutual: both the person providing support and the individual supported must have time and opportunity to get to know each other – and to explore if the relationship will work. Opportunities

"Agencies support the lifesharing household, not just the person with the disability."

Dana Olsen
Pennsylvania ODP

to meet and spend time together before deciding to share lives are critical to assuring the match is right for both parties. The service system has to be flexible enough to permit the development of relationships – and, in fact, encourage relationships that might lead to shared living.²¹

²⁰ "Lifesharing through Family Living," (Mental Retardation Bulletin, Commonwealth Of Pennsylvania- Department of Public Welfare, Number 00-05-04, August 8, 2005).

²¹ As an example, some states do not permit group home or other provider staff to take folks home with them and share their family life – thus prohibiting the potential development of personal relationships. This prohibition means that a rich source of possible life-sharing opportunities is prevented from developing.

Support. The third most essential component of shared living is the support provided to the shared living provider. This means giving them the information, resources and assistance that enables them to focus on the person they are supporting. This includes the support of other professionals, as well as access to consultation, and emergency services if needed.

For shared living to meet the expectation of individualized, customized support, the person providing support must be buffered from the bureaucracy and its regulations and "system" requirements such as paperwork, while afforded the opportunity to establish a true personal relationship with the individual supported. This is not to say that quality and outcomes are not essential to shared living – but how the system sets these expectations and operationalizes them can be either barrier or an enhancement. Careful attention to what rules make sense and what rules don't is essential. Shared living must also provide reasonable financial resources to assure stability. But primarily, the focus is on supporting the growth of the relationship between the individual and the person providing support.

Most DD state agencies assure this support for the shared living provider by contracting with another entity such as a provider agency, a county, or a contracted regional administering agency (see Chapter 3: How States Implement Shared Living).

The Benefits of Shared Living

Most important is the quality of life that people enjoy from having chosen the people they live with – people who care about them, who share life's ups and downs with them. Relationships are at the heart of shared living, including relationships that reach beyond the shared living provider to friends, extended family members and neighbors. Many states report shared living arrangements that are sustained more than 10 and 20 years.

Benefits of the Shared Living Model

- Inclusion in the community has been and continues to be a major focus of supports for people with disabilities. The Shared Living model has proven to be a good means for providing true inclusion in a person's community, if the individual is matched and well supported by the Shared Living Provider.
- Shared Living can provide both a stable support system and a higher quality of life for the person receiving services. The issue of staff people "revolving" in and out of the person's life is minimized.
- Shared Living can also provide a stable, flexible, higher quality of life for the Shared Living Provider.
- This model provides the training and service quality review needed to assure the system (and the person served) of the highest possible quality and cost-effectiveness of the services.

"Shared Living Handbook"

Maine

Office of Adults with Cognitive and Physical
Disability Services

These relationships have survived deaths in the family, divorce, relocations, and even natural disasters. People become committed to each other. They come to "belong" to each other. And belonging opens opportunities to become part of larger networks of families and friends.

Michelle and Larry met Donald under temporary circumstances in June 2003, but immediately felt a bond with him. Soon he'd become part of their family and thus was included in all of their outings and family celebrations.

Life was going so well – but in May 2008, Donald accidentally fell, hit his head, and remained unconscious for four weeks. Michelle and Larry visited him daily. Donald was able to move from ICU to a patient room, and then to a nursing home. Despite others' pessimism, Michelle and Larry maintain their intention to welcome Donald home again.

Pennsylvania

There are, potentially, financial benefits as well. Shared living may be less costly for some individuals than shift-staffed situations – particularly when an individual needs more "customized" supports or one-to-one staffing in order to thrive. Shared living may also provide a measure of stability for the person providing the supports – as well as compensation that is potentially tax deductible (discussed later in this guide).

For the person with a disability too, stability – and permanence – are additional benefits. Living in a real home, seeing the same people every day, and enjoying predictable holiday rituals provide a constancy that is

difficult to sustain in a group home. **Maine's** shared living handbook notes: "Shared Living can provide both a stable support system and a higher quality of life for the person receiving services. The issue of staff people "revolving" in and out of the person's life is minimized."²² **Pennsylvania** reports that out of 842 individuals in shared living, the length of relationships is remarkably stable, particularly as compared to staff turnover rates in other residential settings. They found that:

- 262 individuals shared the same situation for 5 years,
- 126 individuals shared the same situation for 10 years, and
- 75 individuals shared the same situation for 15 years.²³

Shared living requires no building permits or zoning fights: it occurs wherever citizens live – in homes they own, in rental apartments, on the farm or in a condo. The living quarters are individualized and varied – just as they are for citizens without disabilities.

Shared living is also about shifting the balance of power. Done right, with a strong focus on the individual, shared living can alter – indeed eliminate – the power relationship. In true shared living, both the individual with a disability and the person living with him or her gain mutual benefit, living as equals in the same household.

²² "Shared Living Handbook," (Maine Office of Adults with Cognitive and Physical Disability Services, Effective October 1, 2010), p.2.

²³ Pennsylvania Office of Developmental Programs, "FY 2008-09 Lifesharing Through Family Living Directory Lifesharing Agency Survey Results," PowerPoint Presentation, p.5.

Chapter 3:

How States Implement Shared Living

Administering Shared Living

Some DD state agencies administer the program directly. (Unlike some group homes in a few states, no shared living arrangements for adults, to our knowledge, are directly operated using state employees.) But, as with other services, most DD state agencies administer shared living alternatives through another entity, such as a state regional office, a county, a contracted regional administering agency, or an individual provider agency.

Typically this entity:

- Recruits and screens shared living applicants;
- In conjunction with the person-centered planning process, matches the person with a disability and the applicant;
- Provides oversight to the shared living provider;
- Provides ongoing supports to the shared living provider;
- May assist in arranging for support services and respite care;
- May oversee and provide opportunities for training to the shared living provider; and,
- May bill on behalf of individual providers.

As an example, **Vermont** contracts with private, nonprofit organizations, "Designated Agencies" or "Specialized Services Agencies," that provide or arrange for developmental disability services.²⁴ These agencies contract directly with the shared

The family of Judi and John already included a woman in her middle years who had cognitive disabilities, for whom they had been providing care for many years. But after the addition of Deborah, known as Dolly, who was in her late forties, everyone soon became friends as well as family.

But after settling in, Dolly began to develop dementia – with gradual loss of speech and ambulation, and the beginning of seizures. However, Judi and John remained faithful and flexible to Dolly's increasing needs, seeing that she got a custom-made wheelchair and buying an accessible van.

As the years passed and Dolly's dementia worsened, Judi and John continued to be extraordinary advocates. On the internet John discovered how to treat dementia with natural supplements and brought the information to Dolly's doctors' attention. Dolly eventually developed dysphagia and needed an NG tube for feeding and medications. When she could no longer get out of bed, the family sought out a special mattress so that she wouldn't develop pressure sores. In the end, Dolly received Hospice care at home for three months before she passed away in December 2007.

from "Knots That Bind, The Pennsylvania Lifesharing Newsletter"

²⁴ These agencies are also responsible for managing and overseeing other services as well.

living providers for services – but the providers are not employees of the agency. The agency is expected to provide information, opportunities for training, support and oversight to providers, as well as monitoring the performance of the provider and the well-being of the individual. Some of these agencies do assist providers to find respite workers, but more typically, the home provider is responsible for recruiting, training and hiring respite staff.

Maine uses "Administering Agencies" which perform all recruitment activities and approve individual applicants to become providers. These administering agencies also work with case managers and individuals to match individuals and providers. The administrative agencies also provide quality assurance reviews, including monthly visits, and other supportive functions such as billing on behalf of and consultation with the shared living providers who are independent contractors to the administering agency.

Rhode Island's Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH) designates "Authorized Placement Agencies for Shared Living Arrangements" that manage the shared living program. These agencies have the authority to develop and contract with shared living providers. The authorized agencies recruit and match providers and individuals, provide training and ongoing support to providers, as well as submitting payment invoices on behalf of individual providers.

In **Georgia** the state Department of Behavioral Health and Developmental Disabilities (DBHDD) directly enrolls and approves agencies administering one or more host/life-sharing homes as part of their enrollment as a provider under Georgia's home and community-based services (HCBS) waiver.

His smile is infectious and there is wisdom in his eyes. But when he began to hear voices, his beloved 61-year-old, widowed mother felt she could no longer manage his care at home. At age 37, Ed was placed in a group home with five other men. He had headaches and high blood pressure, but eventually the voices were silenced with medication. Here Ed met one staff person that he liked: Dennis, who would take him to his own home from time to time.

Years later, Ed moved to an enclave of six apartments with 24-hour staffing. He liked all the staff there – especially Cathy who often took him to visit her home where he could see his old friend Dennis, her husband.

Cathy and Dennis often thought that when they retired, they would ask Ed to live with them – and then they learned about Rhode Island Shared Living and realized there was no need to wait. Ed joined Cathy and Dennis's family in 2006 and he could not be happier. When Ed was asked what he wanted that first Christmas he responded "I got all I need for Christmas. I have a good home and a nice family!" And anytime you ask Dennis and Cathy about their decision to have Ed share their lives their response is always the same – "best thing that ever happened to us, we get more than we give."

from Rhode Island MENTOR Shared Living Program

Rhode Island's schedule of payments expressly includes a specific administrative payment to the agency managing lifesharing matches. In addition (described in more detail below), Rhode Island pays incentives to move individuals into shared living arrangements. In **Vermont**, the designated agencies fund all of their management costs

through an administrative cost line item in their HCBS waiver. All the individuals in shared living are served through the HCBS waiver.

In **Massachusetts**, the Department of Developmental Services (DDS) area offices (which administer the DD programs) contract with provider agencies, which see to all aspects of the shared living service including recruiting, screening, matching, training, and ongoing case management/monitoring. The area offices are reimbursed for activities including matching, training, and follow-along in the service payment rate.

When David was 14 years old, first his mother, then his father abandoned him. Georgia's staff eventually discovered that David had spent the first four months of his life in a neonatal incubator and had not been expected to live; he also had a history of seizures, ADHD, PTSD, and Intermittent Explosive Disorder; and he later developed insulin-dependent diabetes.

In the early days, it was a challenge to find the right setting for David and his living arrangements were disrupted several times. But finally he was finally matched with Louise, who had worked for the local Arc for more than 20 years, serving adults who had challenges similar to David's. Louise did not give up on David. She learned how to give him his insulin injections, check his blood sugar and monitor his diet carefully. She also learned how to reach David, a child who had been repeatedly disappointed by all adults in his life. At an ISP meeting, Louise told David, "I want you to know that I love you and that you are part of my family. I want to be sure you understand that I will never leave you – I will be with you forever. One day, you may want to be in an apartment with some guys, but I will come and see you -... you will always have a home with me..."

This meeting took place eight years ago. David is now 26 years old. He still lives with Louise. David no longer requires insulin injections to manage his diabetes. His behavior turned around in a near complete reversal on the day of that special meeting... You can see the sense of family and belongingness David has developed when he affectionately calls Louise "Ma".

from Georgia MENTOR Host Home Program

There are, then, many ways to structure the administration of shared living – from using state employees, to working with contracted regional management entities, to using direct provider agencies to recruit, oversee and manage. States can set up an administering agency under the Organized Health Care Delivery System (OHCDS) option and the OHCDS can contract with performing providers. Under this type of arrangement, the state could use Medicaid administrative funding to cover the costs of administering agencies, including the training and oversight they provide.²⁵ In the situation where the agency provides direct services such as case management or person-specific consultation, these activities can be covered as part of the service payment rate.

Whatever the arrangement, laying out the scope of responsibilities – and adequately resourcing the administering agency to carry out the tasks – is critical to the success of the endeavor.

²⁵ For information on OHCDS, see, "Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria," (Release Date, January 2008), p.260-262.

Recruiting Individual Shared Living Providers

The administering agencies have many ways to recruit shared living providers – publicity campaigns using print ads and on-line resources being the traditional avenues. But a key source people who enter into shared living is the group of individuals with whom the person already has relationships – and current and former direct support staff may be the richest reservoir. This can include individuals who work in day and vocational programs as well as individuals who have provided support to the individual where he or she currently lives – either in residential programs or their family home. In the past, one of the strongest sources of shared living opportunities for individuals leaving state institutions have been the staff working in the institutions who have long-standing relationships with the people they supported every day.

As mentioned earlier, one state does not permit direct care staff to take individuals home with them. One can understand the rationale for this, safety perhaps being paramount – and concern for residents of the facility (or others in the program) who may feel left out.²⁶ But shared living requires the suspension of rules that get in the way of nurturing and supporting relationships. And there are other avenues to keep people safe – and to assure they have a network of friends who will take them home too. Careful and thoughtful person-centered planning for all individuals can address the safety concerns – and should be a way to plan for the development of relationships for everyone.

Another possible source of people who may enter into shared living is the extended family. Exploring the extended family builds on the concept of "kincare" used in the foster care system. Shared living provided by uncles and aunts, sisters and brothers, cousins, and grandparents may be an option for some individuals. But, as in all approaches to recruiting people to provide supports, careful assessment and robust person-centered planning are the foundation for making any match.²⁷

Other pools to explore are the family members and friends of existing shared living providers who may have an interest in opening their homes. Then too, people who offer respite may also develop an interest in becoming part of shared living. Building a cadre of respite providers is necessary to support shared living providers, but it also allows agencies to evaluate potential life-sharing home sharers.

Individuals with disabilities are themselves a source of potential providers through their own families, friends and neighbors – if they are aware of the possibility. **Pennsylvania**, as part of the county shared living strategic plan, requires publicity that includes making

²⁶ In another instance, a provider agency cited Department of Labor regulations as a barrier to allowing direct support professionals to socialize with individual they are paid to support. This may be a misinterpretation of regulations governing the scope of paid duties versus socializing on the support worker's own, unpaid time and is worth exploring with the state's Department of Labor.

²⁷ For a discussion of family members as providers, see Robin Cooper, *Caring Families, Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities*, (NASDDDS, June 2010), p.20-22.

the option of shared living known to consumers and families. Additionally the county agency is expected to make information about shared living available at conferences and provider fairs, as well as through the media.

Rhode Island has taken a bold step in recruiting providers. Beginning in January 2010, Craig Stenning, the Director of the Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (DBHDDH) introduced a program to attract and retain shared living providers. With an eye to transforming their service system, "to provide better outcomes...and [to] sustain basic services," Director Stenning set up a series of incentives – from half the saving realized when an individual moves from a more costly placement into a shared living arrangement. Once an agency has been involved for six months, eighty percent of the saved amount is paid to the agency moving an individual out of a group home and twenty percent is paid to the agency providing the new home. These incentives are part of DBHDDH's efforts to promote shared living as, "an important alternative to group homes since in the last analysis those who participate seem to thrive and the cost is half of that of a group home placement."

Making the Match

Shared living is all about the relationship. The match between the individual and the person offering companionship is the single most critical element of the success of shared living. While other elements such as training, support and compensation also affect the success of shared living, the relationship between the individual and the person living with him or her is paramount. Strong, committed, compatible relationships are pivotal to weathering the ups and downs of daily life.

As **Georgia's** "Host Home/Lifesharing Operating Procedures" notes, "*Life-Sharing is a process*. A key to successful Life-Sharing is finding a family or person to share their lives with an individual with developmental disabilities. The matching process between people who want to Life-Share is critical to predicting future success of the relationship."²⁸

Success in making the match requires an investment of time and resources. In **Massachusetts**, one of the managing provider agencies offers this advice in their brochure: "The process is very individualized and can take several months once a person and/or their family decide to pursue shared living. Finding the best possible match, with respect to a provider, is paramount and recruitment and selection can take some time."²⁹ **Pennsylvania** recognizes that making a successful match requires an investment of resources to cover the start-up time. They advise their counties that, "In order to make a successful match, three to six months startup funding is needed to

²⁸ "Host Home/Life-Sharing Operating Procedures," (Georgia Department of Behavioral Health and Developmental Disabilities, Revised April 1, 2011), p.4.

²⁹ "Shared Living Program Questions and Answers for Families," (HMEA, Franklin, Massachusetts), <http://www.hmea.org/documents/FamiliesQ&A.pdf>.

facilitate the development of relationships and place a person in the county where they want to live."³⁰

Making the match not only requires time – attention to specific steps in the process can make for greater success. Initially there is an interview process with the individual with a disability. Understanding the expectations and preferences of the individual is the foundation of future success. True person-centered planning is the basis for beginning a move to shared living. Knowing that an individual dislikes dogs or is a real "night-owl" is essential knowledge to the success of a match. **Pennsylvania** uses an extensive "Individual Profile" that asks about the individual's preferences, including food and religious orientation, along with a considerable amount of other information: topics such as whether the person prefers an urban or suburban setting, his or her preferences about smoking and the type of bedroom the person likes. This profile forms the foundation to begin the matching process.

Attending to the concerns and expectations of the individual's family members (or guardian or others who are part of the person's life) is equally critical. There is no need for a living arrangement to fail because a family member is dissatisfied with something that others did not see as critical – perhaps the quality of housekeeping in the home or the household routines. While the focus certainly must be on the individual, family expectations and concerns need to be addressed as well.

Some families may also balk at the idea that another family will be caring for their family member – now that they are unable to. At times, families have asked for group homes, feeling that if their family cannot care for the individual, then a group home is the only alternative. Some families may express fears that they are being replaced by another family. Sensitivity to maintaining and honoring birth family relationships then becomes critical (as it should be in any planning process). **Maine** noted that creating a relationship between the family and the potential provider host family or individual is essential. Maine staff indicated that often a way to establish a relationship is through the use of the potential provider as respite: Both the birth family and the provider get to know each other, and this also acts as a "trial" placement and a means to figure out if the situation is a good match.

Interviewing potential candidates is also an important step to finding a match. And even if the individual with a disability brings someone forward as a potential candidate, the same interview process is important to confirm the candidate's motivation. An understanding of the candidate's own family dynamics is also important; especially if there will be other members of the provider's family in the household. Candidates' interests, hobbies, preferences, community memberships, and of course their own expectations about sharing their life with an individual with a disability – all affect the quality and permanence of a match. Sometimes challenging and delicate conversations are required to explore the provider's values, beliefs and attitudes about intimate relationships and even spiritual or religious pursuits. The same concerns about any

³⁰ "Lifesharing through Family Living," (Mental Retardation Bulletin, Commonwealth Of Pennsylvania · Department Of Public Welfare, Number 00-05-04, Date of Issue August 8, 2005), p.3.

relationship – shared values, compatible lifestyles and tolerance – are critical to the success of shared living.

But in order to make the determination that the match can work, there is no substitute for spending time together. Relationships are built on shared experiences. Spending time with each other in a variety of settings and activities is important to making the assessment about the match. Thus, as with the other activities needed to make shared living a success, resources must be made available to support building the relationship.

Qualifying the Shared Living Providers

Most states have some type of certification standards and/or regulations. The review (certification or licensing) may be conducted by a state agency or the managing entity. Some states require that a shared living provider obtain specific licensing – for example, as a foster care home – while others have certification standards but do not require licensing. No matter what method, all states have a rigorous approach to assuring that the individual(s) providing support have the background, attitudes and competencies needed to be a shared living provider.

Maine's application is very candid: "In order to be considered as an independent contractor to provide services, it will be necessary to answer some very personal questions regarding yourself and members of your household." In Maine, the administering agencies certify the provider once the provider has met the following conditions:

- Successfully passed background checks, along with all other family members who live full- or part-time in the home or who will provide support to the individual;
- Successfully passed interviews and home visits to assure that the provider is both qualified to provide services and has a home that meets all health and safety environmental standards;
- Successfully met training requirements [discussed in section below]; and
- Verified that he/she has time to provide daily services/supports that meet the needs of the individual and to work towards the goals identified in the Person-Centered Plan.³¹

Georgia's Support Coordination Agency, or the DBHDD designee for any individual choosing shared living, inspects the home using the approved state Division of Developmental Disabilities site inspection tool prior to an individual with developmental disability living or receiving care in the home. As with other states, the home study looks at the physical characteristics of the home as well as the provider's family dynamics and experience and expectations. The home study asks about the provider's motivation and attitudes towards individuals with disabilities – including attitudes about dating, and about how other family members might react to an individual with disabilities.

³¹ "Shared Living Handbook," (Maine Office of Adults with Cognitive and Physical Disability Services, Effective October 1, 2010) p.3.

Pennsylvania uses an application and home study process that is specific to shared living. The questionnaire seeks information about the physical aspects of the home, about the neighborhood, and about the potential lifesharing provider and their family (if applicable). Pennsylvania, like most states, also requires references and criminal background checks as a routine part of the application. Once an application is accepted, Pennsylvania does an actual on-site home study that looks at critical safety issues, comfort and neighborhood characteristics.

Key to qualifying these shared living providers is the attention to both the physical site and safety. But an intensive focus on provider attitudes and values and motivation is important to ascertain if the provider is "cut out" for shared living.

Paying Relatives

In a 2010 NASDDDS survey (not specifically on shared living), 46 of 48 states indicated that they pay relatives to provide services, with 36 states paying parents of adults with disabilities to provide transportation and support.³² With workforce shortages and the rural nature of many states, family members are often a critical source of supports. Many of the states also indicated that they pay family members to provide shared living. As discussed at length in the monograph, *Caring Families... Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with*

SURVEY RESULTS: Paying Relatives for Care	
Total number states responding N=48	
Type of relative paid	Number of states
None	2
Parent of a minor child	6
Spouse	10
Guardian of child	6
Guardian of adult who is a parent	21
Guardians who are other relatives	23
Guardians who are not relatives	18
Parents who are not legally responsible (parents of adults)	36
Siblings	44
Grandparents	45
Other relatives	46

Disabilities, there are many strengths in using family members to provide supports.³³ The person is known to the family and families care deeply about their family member. Relatives can be a stable source of supports. And while there may also be concerns that must be addressed – such as guaranteeing that the individual has strong opportunities for choice and control, along with age-appropriate activities – as with any successful shared living situation, it is all about the matching process.

³² Robin Cooper, *Caring Families... Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities*, (NASDDDS, June 2010).

³³ The publication is available for purchase through the NASDDDS website, <http://www.nasddds.org/pdf/PubsOrderForm.pdf>.

Training for Shared Living Providers

Most states have initial training requirements to become a qualified provider, along with ongoing opportunities and requirements for training. States typically require CPR, training in recognizing and reporting abuse and neglect, and safety awareness (such as fire safety or disaster planning). Some states require training in "core values." **Maine** requires training in basic medication administration (among other topics) and compensates their providers for taking this training. Also, Maine has adopted the College of Direct Support training program for those in shared living (in addition to other direct support professionals).³⁴

Georgia requires fairly extensive training (see sidebar). And most states also require providers to take specialized, person-specific training to assure that the needs of the individual are understood and well-supported.

Massachusetts's requirements explicitly reference person-specific training – which is typically identified in the person-centered planning process along with the time frames for completing the training.

Georgia's Pre Service/Annual Training

The adult family member who shall have primary responsibility to the individual and for providing services to the individual shall have at least the following training *prior* to the DBHDD provider agency making application for a site specific Medicaid provider number:

- ☐ Person-centered values, principles and approaches
- ☐ Human Rights and responsibilities
- ☐ Recognizing and Reporting Critical Incident
- ☐ Individual Service Plan
- ☐ Confidentiality of individual information, both written and spoken
- ☐ Fire Safety
- ☐ Emergency and disaster plans and procedures
- ☐ Techniques of standard precautions
- ☐ Basic cardiac life support (BCLS)
- ☐ First aid and safety
- ☐ Medication Administration and Management/Supervision of Self-Medication

Georgia provider manual,
*"Host Homes for DBHDD Developmental
Disabilities Community Service Providers,"*
6-29-10, p. 3

What Does the Shared Living Provider Do?

The paramount responsibility of a shared living provider is to collaboratively make a real home where the person providing supports and the individual have a mutually satisfying and meaningful relationship: a home that really feels like a home to everyone. This is particularly important if an individual moves into the existing home of the person providing supports. The individual being supported is not just moving into a room in someone else's home – they are sharing that home in the fullest sense. Changes in routines and compromises may need to be worked out to accommodate really sharing

³⁴ For information on Maine's use of the College of Direct Support, go to www.maine.gov/dhhs/OACPDS/DS/cds/index.shtml.

the home with a new member. It is not only the responsibility of the individual moving in to adjust – everyone in the home has to be willing to make adjustments and come to mutual agreement and understanding.

At the most basic level, the provider is there to help make a home that suits everyone – a home that is comfortable, with good food of everyone's choosing. Establishing likes and dislikes or cleanliness tolerance is part of the planning process. But as anyone knows who has ever lived with another person, while planning can help, the reality of living together requires ongoing attention and understanding. The provider has to be able to assist the individual to integrate into the setting – and be willing to change themselves in relation to the person supported.

Shared living means sharing all aspects of life, both at home and in the community. Friends, families, neighbors and civic organizations are all part of the wider circle of life that enriches the life of the person with a disability by expanding the potential number of relationships with people who are not paid – their "circle of friends."

The provider takes on responsibilities that include assuring the health (including proper medical care), safety and well-being of the person supported. But assisting someone to take reasonable risks is also a part of the shared living provider's role. Understanding the interplay of risk and opportunity is critical for a person providing shared living. So, as will be discussed later, the shared living provider also needs support in this area.

"We must give up the mindset of the service system being all knowledgeable and the inimitable protector over people who are deemed to be different. We need to listen more carefully to those who come to us for support and we need to support them in becoming involved in valued and honored roles with others. We need to support the development of ordinary relationships between those with and without disabilities."

"Sharing Lives", Pat Fratangelo,
Onondaga Community Living,
TASH Newsletter, Volume 32, Issue
9/10, September/October 2006, p.7-8.

Beyond the home itself, shared living is about making a life as a member of a community. This means that another key responsibility of the shared living providers is assisting the individual to become part of the larger community – within the framework of the person's own interests and preferences. The issue of community connections is an important part of making the original match. If the person supported has limited community connections – and a desire to expand those connections – then the person offering support needs to be someone who either already has a wide array of community ties or who is comfortable with seeking out new relationships. As the New York State Association of Community and Residential

Agencies (NYSACRA) states, "Shared or supported living is more than just being *present* in the community. It is about being a *valued member of the community*. Membership means both being welcomed by and contributing to the community....individuals, their circles of support and agencies [and/or individuals] providing shared or supported living must vigorously and creatively work at assuring the

individual participates in and contributes to the community in ways that are in keeping with his or her personal choices and desires."³⁵

Supporting Shared Living Providers

Supporting the individuals providing shared living can occur in a variety of ways – from making available training and consultation services to helping make sure that the individual with a disability has a job and opportunities to engage in community activities. As an example, **Vermont** describes a number of "complementary" supports offered to those in shared living arrangements which include home and community-based services such as employment supports, respite or other community supports.

Other states provide what are called "supportive services" that assist the provider and the person supported by offering consultation and other services to help maintain a positive relationship. For the individual being supported, these complementary supports include companion services, vocational and educational possibilities, self-advocacy groups and other opportunities to develop skills and interests. For the shared living provider these supports range from additional training opportunities to respite and consultation services.

Ongoing Training

In addition to the initial training needed to become a qualified provider, ongoing opportunities for training are often a part of the supports offered to shared living providers. Opportunities to learn about specific new approaches to supporting individuals – as well as to attend conferences and meetings with other shared living providers – can be a source of support for providers. **Pennsylvania** created a state subcommittee called the lifesharing committee whose mission is to "promote, support and embrace the concept of lifesharing and the philosophy of self-determination." This group meets regularly, as do its four regional subcommittees. The statewide and regional meetings are open to anyone interested in promoting lifesharing. As the brochure describing the subcommittee notes, "These meetings provide wonderful opportunities for provider agencies and lifesharing families to organize events and to share information and experiences." This type of learning network is a very positive way to afford opportunities for formal and informal training – and to support the efforts of the individuals and families who participate in shared living.

As noted earlier, **Maine** uses the College of Direct Support for initial and ongoing training and, reimburses providers for the costs of the training. **Massachusetts** also offers compensation for ongoing training provided through the managing agencies.

³⁵ "Creating Innovative, Individualized Living Options for Persons with Developmental Disabilities; It's not about a model; it's about an approach," (New York State Association of Community and Residential Agencies, Prepared for: New York State Developmental Disabilities Planning Council, December 2009).

Georgia offers no-fee, ongoing training, including topics such as, "*Host/Life Sharing Home Philosophy and Guidelines Training*."³⁶

Networking with Other Providers

Peer-to-peer networks are a critical source of support for providers. These networks offer opportunities to meet with other individuals engaged in shared living to discuss concerns and share experiences. States can support these efforts through assisting with the coordination of these groups by providing resources for conferences and training events – and even by just attending various meetings and events put together by provider associations or the shared living managing entities.

As mentioned above, **Pennsylvania** has a structure that offers those in home sharing regional and statewide meetings on a planned basis. This creates opportunities for individuals to learn from each other and creates a readily accessible network of peer supports for those involved in lifesharing. As one Pennsylvania official noted, these are not, "isolated mom-and-pop's – there is a network." In **New York**, NYSACRA provides an umbrella organization, which has regional meetings, to assist providers, offer learning opportunities and act as a network of peer-to-peer supports. In **Massachusetts**, some of the managing agencies hold regular, required meetings for both "educational and social" purposes.

Support Coordination/Case Management

As with any array of supports and services provided under state and federal funding, shared living is subject to oversight and involvement by support coordinators (or case managers or case coordinators – or whatever term the state uses). This role is discussed in more detail below under the quality management section.

Support coordinators typically fulfill the same types of requirements with shared living as they do with other services. They may convene and facilitate the person-centered planning, assist the individual in selecting supports and of course provide consultation and monitoring to the service providers. But beyond the usual support coordination, some states and managing agencies have gone a step further, providing supports coordination that is specific to, and dedicated to, supporting the shared living arrangement.

Specialized Shared Living Supports Coordination

Pennsylvania's system funds qualified professional lifesharing specialists who work only with individuals and providers engaged in shared living situations. As described in Pennsylvania's guidance about life sharing, the "Lifesharing Coordinator" functions include regular visits and contact with the lifesharing home, training and communication with outside agencies and supports coordinators." The coordinators each provide

³⁶ Georgia Department of Behavioral Health & Developmental Disabilities, Training Announcement, "*DD Host/Life Sharing Home Philosophy and Guidelines Training*," (October 19, 2009).

support to eight homes. The fee structure for shared living includes both the payment for the actual shared living provider as well as payment for these coordinators other supports and administrative duties. In licensed situations, Pennsylvania provides for support through the use of family living specialists. In both cases the caseload is limited to a maximum of 16 individuals or eight homes. Pennsylvania recognizes that shared living is different from other residential supports and advises the managing agencies

RHODE ISLAND SPECIALIZED SUPPORT COORDINATION

In order to effectively support shared living arrangements, the support coordinator shall, at a minimum, have some combination of education, training and experience in the following areas:

- Supporting adults with developmental disabilities in community settings
- Developing individualized community based supports
- Family Systems
- Creative problem solving
- At a minimum, the support coordinator shall have face to face personal contact with the individual and/or home provider at least:
 - Weekly during the first two months of placement; and
 - Once a month ongoing for the duration of the placement.
- Personal contact shall include a combination of the following:
 - Visits with the individual alone
 - Visits with the home provider alone
 - Visits with the individual and home provider together
 - Personal contact shall occur in the home and community.

*"Standards for Authorized Placement
Agencies for Shared Living Arrangements,"
State of Rhode Island, Department of Mental
Health, Retardation and Hospitals, Division of
Developmental Disabilities, August 23, 2007*

that, "Due to the differences in supporting lifesharing and other forms of community residential support, such as community homes, ODP recommends that family living and lifesharing specialists will be assigned to only support lifesharing homes whenever possible."³⁷

In **Rhode Island**, the managing agencies have dedicated staff who provide support and solve problems. As Rhode Island's shared living arrangements guidance notes, "The role of the Support Coordinator is integral to the success of a shared living arrangement. The agency must have the ability to respond to a wide range of situations that may arise in shared living arrangements, and to problem solve when necessary."³⁸ Rhode Island details a list of expected competencies along with an extensive scope of duties that the support coordinators perform. Dedicated support coordination can be of great benefit, particularly when an individual has complex needs. The type of intensive support that some individuals need may be beyond the scope of duties of "regular" case managers, particularly those who carry large

³⁷ Pennsylvania Office of Developmental Programs *Lifesharing Safeguards Bulletin*.

³⁸ "Standards for Authorized Placement Agencies for Shared Living Arrangements," State of Rhode Island, Department of Mental Health, Retardation and Hospitals, Division of Developmental Disabilities' August 23, 2007, p.7.

caseloads. Providing support to both the individual and the shared living provider can be the critical factor in maintaining and preserving the arrangement. A skilled coordinator who understands family dynamics and the interplay of relationships can assist both the individual and the person offering support to establish a stable and mutual relationship.

Consultation and Intervention Services

For individuals served in shared living arrangements who have medical, behavioral or mental health concerns, access to clinical consultation and support may be critical. Offering hands-on, in-home support to both the individual supported and the provider may be what keeps the situation stable and positive. In **Massachusetts**, the managing agencies provide a nurse and consultation from a behavioral clinician, as well as access to crisis, emergency, and safety management supports.³⁹

Administrative Support

In several states, including **Maine** and **Rhode Island**, the managing or administering authority provides billing services for the individual shared living situation and in turn pays the providers. This reduces the administrative burden on providers and assures that billing and payment are timely and correct. Other types of support include using the managing entity to perform background checks or to collect reports of incidents such as medication errors. In some states, the managing entity can provide or arrange for emergency backup if the individual providing support is unable to continue to do so.

Respite

Time apart can be critical to the health of relationships and should be addressed in the person-centered planning process. The need for, and the amount of, planned time off varies with each individual situation. In many instances, the individuals sharing their lives will come to agreement on time spent together and apart – particularly when the supported individual is able to spend time alone without support. For individuals who need support on a more continuous basis, planning for time apart is important to the well-being of both the individual and the provider. And respite time is not just for the person providing support – it can allow the individual being supported to form other relationships and/or have access to activities not typically a part of the shared living relationship.

There is considerable variation in how relief or respite time for shared living providers is handled. Arranging and paying for respite is the responsibility of the shared living provider in some states, while others resource and arrange for respite services as a part of the individual planning process.

Some states include provision for respite in the compensation paid to the shared living provider. **Pennsylvania** compensates the provider for up to 31 days of temporary

³⁹ Minute Man Arc, SHARED LIVING brochure, found at http://www.minutemanarc.org/images/Shared_Living_brochure_032910.pdf.

respite care. Compensation may also include payment for emergency respite services based on the needs of the individual supported and the individuals providing support. **Vermont** uses this approach including a monthly respite allocation in the person's individual budget. It is expected that the shared living provider will recruit, hire, and train their own respite workers, although in some instances the managing agencies assist with finding respite workers. **Georgia** offers up to 30 days of what they term "alternate care" to the shared living provider. This care may be provided in the home of another qualified host home or lifesharing home provider.

Other Supports

Typically individuals in shared living also have other supports including vocational or adult educational services, and opportunities to engage in community activities, self-advocacy and the development of skills and hobbies. While some of these may involve the individual providing support, often individuals receive paid and unpaid services and supports through other organizations or providers, as determined through the person-centered planning process. In some instances, when the person providing support is paid to provide services on a 24/7 basis, the shared living provider may hire – become the employer of – other individuals to provide, for example, vocational supports. In **Vermont** this type of arrangement is permissible and the payments to the workers hired by the provider are made through a Fiscal Intermediary Service Organization (Fiscal ISO).

The person providing support and the individual supported both need time apart and time to pursue interests and activities they do not choose to share. While respite can help, for the person supported, planned involvement in work or in pursuing interests and hobbies apart from the shared situation is typical of how most citizens live in our culture. Individuals who share their homes do not spend every waking minute together – and often may have interests that are not shared. Actively planning for individual development outside of the shared relationship is important to the long-term health and stability of the shared living relationship, as with any relationship. In some instances, depending on state regulations, individuals offering support may have other employment as long as they are available to provide the degree of support determined through the person-centered and in keeping with the compensation they receive (see "Outside Work" on page 37).

Opportunities for the individual supported to participate in self-advocacy training and organizations can add to the success of shared living. Individuals with disabilities need to have the skills to make their concerns known; this is of benefit both to the person and to the provider. Self-advocacy – and participation in other community activities – also allows for the development of relationships and for activities that do not rely on the shared living provider, thus giving individual another chance to spend time apart.

Making the Rules Work for Shared Living

As it is said, "Life is messy." And sharing lives? Even messier. In general, residential services rules were established to support group settings and were built off of the regulations for ICFs-I/DD. Residential regulations typically include requirements for providing habilitation services with specific goals and objectives, detailed documentation of progress toward these goals, intensive health and safety requirements, and physical plant licensing requirements. These requirements relate to the fact that a *group* of individuals live together and are intended to make sure that the individual's rights, health and safety are assured and that there is documentation of the approaches and "programs" designed for the specific individual. The requirements also address the need for a continuity of support even as the individuals providing that support change, in many situations, three times a day. This structure and these intensive documentation requirements and rules are meant to be safeguards that ameliorate the effects of shift staffing and staff turnover that are endemic to group residential services. In some states, in group living arrangements the interactions among individuals and staff are also regulated. As noted earlier, there may be regulations and policies that govern the personal interactions among staff and "residents," not allowing staff to form personal relationships with the individuals supported outside of the workplace. Staff may not be permitted either to drive individuals to outings or to accompany individuals to some community settings.





In licensed programs, zoning requirements may have to be met, staffing patterns may require detailed descriptions of overnight coverage and intensive documentation of habilitation activities. These requirements all relate to "service life" – not life as a citizen, in a home in the community. Even when shared living develops within the home of the person providing support, these types of rules and regulations do not support the flow and complexity of a shared daily life based on stable, lasting relationships among a few individuals.

That is not to say that shared living situations are exempt from assuring quality, safety, and well-being. But the regulatory overlay can affect the ease and success of shared living. Some states include shared living under existing categories such as host homes or adult foster care. While sometimes this can work well, it can also serve to constrain or structure the shared living arrangement in unintended ways. Sensitivity to the possible effects of using existing rules previously developed for another kind of service model is important. For shared living to grow and thrive, each state will need to examine the existing rules to see if they result in unintended constraints or requirements that do not add anything positive to the outcomes and quality of shared living.

Documentation

Intensive documentation requirements may interfere with the natural flow of everyday life. Medicaid reimbursement rules may require daily documentation of the provision of services. But federal Medicaid regulations do not specifically dictate the nature of this documentation – just that it be sufficient to support billing and to show how the supports

are meeting the person's outcomes as identified through the person-centered planning process. So documenting daily life may take the form of a blog, a journal or a diary. This same approach can be applied to shared living – giving both the person supported and the provider an opportunity to perhaps review the day together and jot a few notes that will fulfill reporting requirements, but can also be a way to document a life. This documentation might also be in other forms. As a part of person-centered approaches to supporting individuals, Michael Smull uses the concept of a daily "learning log."⁴⁰

things I have been doing				
Date 	What I did	Who was there? 	What was good? 	What was not good? 
	Think about: <ul style="list-style-type: none"> • When it was • Where it was • How long it was for 	Think about: <ul style="list-style-type: none"> • Did you like them being there? • Who else would you have liked to be there? 	Think about: <ul style="list-style-type: none"> • I liked • I felt • I want more • I learned 	Think about: <ul style="list-style-type: none"> • I did not like • I felt • I want less • I learned

With a learning log the focus is on learning. Rather than a chart or checklist of activities, documenting what happened – and what worked and didn't – such a log both serves as a record of activity and allows for ongoing learning for and about the individual. The natural rhythms of life do not lend themselves to documenting how many times someone tried an activity and the "success" rate. (Often documentation consists of recording "progress" toward activities of daily living goals – such a tooth brushing or buttoning – that have little to do with the desired activities and outcomes the person may have identified as important to them in the person-centered planning process.) Learning logs – or blogs or journals or diaries – thus allow the individual supported and the person(s) offering support to better understand each other and learn from daily experiences, while still fulfilling daily documentation requirements.

Medications and Nurse Practice Acts

State Nurse Practice Acts – or interpretations of the acts – have created some challenges in figuring out how to give medication to individuals in shared living who may need support. In group living arrangements in some states, nurses come in to give medication or supervise those who do. This is clearly impractical when individuals are not living in groups – there are just not enough nurses. And as individualized living arrangements continue to grow, the demand will surely exceed the supply.⁴¹ **Georgia** reports that, at present, either the shared living provider supervises self-administration of medications or a nurse goes into the home and administers medications. This is because, although shared living situations do not operate under a license, these situations are included in the overarching residential services rules. Georgia has passed new regulations that allow "proxy caregivers" to perform certain health-related

⁴⁰ Michael Smull, "Becoming a Person Centered Organization" (October 2005), found at <http://www.unc.edu/depts/ddti/powerpoint/ot10-05.ppt>.

⁴¹ "By 2025, the shortage in RNs is projected to grow to an estimated 260,000 FTEs, twice as high as any US nursing shortage since the 1960s." American Association of Colleges of Nursing: Nursing Shortage Fact Sheet. September 2010 found at <http://www.aacn.nche.edu/Media/FactSheets/NursingShortage.htm>.

activities. Implementation of this new rule will take effect at the renewal of their HCBS waiver and will then apply to shared living.

In **Vermont** nursing responsibilities can be delegated to home providers as long as there is appropriate nursing oversight in accordance with the Nurse Practice Act. Vermont actually has separate regulations for shared living providers regarding medications. Shared living providers must have training and must track medications but the state does not require the same level of nurse oversight as in other settings. Delegation for shared living providers to administer medications comes directly from the person's physician at their medical appointment. This is much more analogous to community life – where the person's own physician, family, spouse, partner, or roommate may assist in giving medications and in making sure the individual is not experiencing any problems related to medications.

The 2009 AARP publication "*Building Adult Foster Care: What States Can Do*" offers considerable information about how states approach the issue of nurse delegation in foster care settings. The publication offers three regulatory models for dealing with medications and other health-related tasks that states can adopt.⁴² These models include:

- **Exemption** specifies that nurse practice regulations do not apply to some categories of unlicensed persons who provide care and support;
- **Delegation** allows nurses to assign specific tasks to unlicensed individuals once the nurse has done an assessment of the supported individual's needs. Typically in this model the licensed personnel verify or certify the competencies of the unlicensed person providing care;
- **Unlicensed Assistive Persons Certification** allows unlicensed individual becomes certified to provide certain services and supports under the training and supervision of licensed personal. This is the model most typically used in institutional settings (or group living such as assisted living for seniors) where individuals operate under close nurse supervision.

Licensing and Certification

Some states choose to license shared situations while others do not. States that use the foster care/host home model, when an individual moves into the home of the person providing support, tend to license the home. And some states license some settings and not others. In **Pennsylvania**, shared living is not licensed when an individual moves into a provider's home and needs less than 30 hours a week of supports within the home. **Vermont** also does not license shared living situations and **Maine** certifies the provider once all qualifying requirements are met.

⁴² Robert Mollica, et al., "*Building Adult Foster Care: What States Can Do*," (AARP Public Policy Institute, September 2009), p.35, assets.aarp.org/rgcenter/ppi/ltc/2009_13_building_adult_foster_care.pdf.

When individuals choose to share a home that either belongs to the person supported or is a rental that they share, most states qualify the individual providing supports, not the place. Again, many of the safeguards that are a part of licensing relate to a facility-based model that serves multiple individuals. Square footage requirements, posted menus, and the like are not a feature of typical community life. The same questions citizens have about where they want to live are the real guide for shared living. Rather than a license, a home study and the person-centered plan and ongoing quality oversight and monitoring can address concerns about the adequacy, safety, and functionality of the home in relation to the individuals' preferences and needs. It is the integrity of the planning process and quality oversight that is critical to the success of the shared living situation, not necessarily the licensing.

Siblings Donald and Diane were in their fifties. Suddenly they'd lost their mother with whom they had lived in seclusion their entire lives. They lacked even the basic living skills: they ate with their hands, slept on the floor, did not know how to shower or properly use the bathroom – even taking a walk outside was a new experience. While Donald had good verbal skills and was a talented artist and musician, he needed guidance with the everyday social interaction. Diane would not speak; she cried often and clutched an automotive trading magazine for comfort.

Ryan and Sheryl are a quiet couple – but full of strength, determination, compassion, a sense of humor, and a deep devotion to those in their care. To look at Donald and Diane now, you would not believe how significantly Ryan and Sheryl were able to increase their independent living skills. Donald is now a polite and social man who enjoys eating at restaurants, playing music for crowds and selling his work at art shows. Diane will answer questions independently, takes great pride in completing household chores, and will initiate conversation on her own. She often exclaims, "I love you!"

And Ryan and Sheryl have done all of this with no expectation of recognition or tribute – indeed they often seem embarrassed when asked if they can be used as examples of how Shared Living can provide people with disabilities with loving, integrated community living experiences.

from California MENTOR

"Outside" Work

Some states allow the provider to have outside work in addition to being paid for shared living, while other states have a blanket prohibition against this. In some instances, based on the person-centered plan, the shared living provider is paid to be available to provide support on a 24-hour basis and so must be available full-time to the person supported. While this ban would make sense if the individual required 24/7 support, there are many instances where the individual does not need eyes-on support at all times.

In some situations, as part of the person-centered planning, it is agreed that the individual may be alone at home without supervision for some amount of time.⁴³ For

⁴³ Vermont has "Home Alone" guidelines that state: "The process for considering when an individual may be home alone includes: 1) determining that the individual has no medical, emotional or behavioral issues that pose a significant health or safety hazard if the individual were to be at home alone; 2) use of an assessment which measures demonstrated skills for remaining home alone; and 3) not requiring that the

some individuals, the payment is then based on intermittent support. Either way, it is helpful to have enough regulatory flexibility to customize the arrangements regarding outside employment – blanket prohibitions can have the effect of quashing situations that otherwise might work well.

Financing and Reimbursement

Because it is not a "model" or "placement type", there are many ways to finance shared living. Some depend on the nature of the situation, others on whether or not the state chooses to license settings or to qualify the situations for federal tax exemptions. Financing can cover an expectation of supervision and training, or simply reimburse rent or food, companionship or just being a roommate.

The main source of financing for shared living comes through the Medicaid program. Various Medicaid authorities including the state plan, HCBS waiver, 1115 research, and demonstration waivers and new options such as 1915(i), 1915(j), and 1915(k) may offer avenues to finance different approaches to shared living.⁴⁴ Despite some of the requirements that come with each of these funding options, states have surprising flexibility in covering options that support shared living. Personal care, companion services, live-in caregiver, host home/foster care, and supported living are some of the types of Medicaid-reimbursable services that can support shared living. Below we look at options that can be used to finance shared living offered in the home of the individual or in the home of the person providing support.

Shared Living in the Home of the Individual(s) Providing Support

The most common way states seem to use to finance this type of shared living is through a host or foster home model. As noted earlier these situations can be either licensed or unlicensed (although of course qualified). Most typically these payments are a monthly stipend. Most states use the HCBS waiver to finance the arrangements, although for some children who are in the custody of the state, other resources such as Title IV-E funds may come into play. Room and board costs, as in other residential situations, are covered through the individual's income, earned, and unearned. For children, room and board costs may be covered through funding from the placing children's services agency. Again, room and board payments are always considered income for the provider, but payment for support may be considered as a "difficulty of care" payment in some circumstances and is tax exempt.

individual remain in a home alone (it's a choice)." from *"Shared Living in Vermont: Individualized Home Supports for People with Developmental Disabilities 2010,"* State of Vermont, Division of Disability and Aging Services, Department of Disability, Aging and Independent Living, p.16.

⁴⁴ See Appendix A, "Comparative Analysis of Medicaid State Plan Waivers & Amendments" for a chart describing these different authorities.

Payment Rates for Shared Living in the Home of the Individual(s) Providing Support

There are no national statistics specifically on the cost of shared living. Some data exists for adult foster care – but this includes populations other than individuals with intellectual disabilities, and thus does not work well for comparison. At best, we can offer a few examples that describe different ways to approach the payments.

In **Pennsylvania**, during the fiscal year 2007-2008, the average paid to the actual provider of shared living services was \$1,746/month. The rate paid to the managing agency was \$43,684, or \$3,640 a month, which includes the payment to the provider. The managing agency rate includes the cost of qualified professional lifesharing specialists (one for each eight homes, as described earlier) and other support and administrative services.

Maine uses a per diem system. The shared living provider receives \$2,500 per month and the administrative agency receives \$1,833 per month for administration, oversight and respite. Maine has allowed two persons to be supported in shared living under very specific criteria. The rate of reimbursement for the entire program for the two individuals is unchanged; the per person costs are divided between the two individuals.

Vermont uses a monthly stipend that is based on the assessed support needs of the individuals and the skill levels and experience needed by the provider. Data from 2009 indicated an average cost of \$2,418 per month, but rates vary considerably as they are highly individualized.

Rhode Island uses a monthly stipend and a level system that provides rates related to the intensity of the support needed. Funding guidelines for 2006 give a picture of the rate ranges and the different components that make up the rate which is paid to the authorized administering agency that provides other supports, including case management.

Rates will vary depending on what components are included in the rate and what stands outside. Some states include a payment for respite services, while others resource this as a distinct service, outside of the rate paid the provider. Administrative and support costs for the managing entity may be included – or again they may be paid separately

Rhode Island FUNDING GUIDELINES, November 10, 2006				
Cost Categories	Level 1	Level 2	Level 3	Level 4
Stipend	\$15,000	\$18,000	\$27,000	\$32,000
Respite	\$ 6,000	\$ 6,000	\$ 6,000	\$ 6,000
Case Management	\$ 5,000	\$ 6,000	\$ 8,000	\$10,000
Administration	\$ 3,320	\$ 4,466	\$ 4,821	\$ 5,584
Recruitment	\$ 1,000	\$ 1,000	\$ 1,000	\$ 1,000
TOTAL	\$30,320	\$35,466	\$46,821	\$54,584

as either an administrative charge or as other distinct services such as case management. Again, since there is no current

national data set on shared living, the best proxy we could find is a study that assesses the cost differential between one model of shared living – Host Homes – and other residential settings. This 2006 University of Minnesota study found that "[p]ersons living in host family or companion arrangements had average social support and medical expenditures (\$44,112) that were 71.4 percent of the average for all HCBS recipients and 34.4 percent of the average for ICF/MR residents."⁴⁵ But with no detailed individual state data, and with the variation in how rates are established, it is virtually impossible to make any accurate state-to-state comparisons.

Difficulty of Care Payments and Tax Exemption

A number of states make use of a section of the federal tax code that permits certain provider reimbursements, called "difficulty of care" payments, to be exempt from taxation. Difficulty of care payments are defined under section 131 of the Internal Revenue Code as: "...compensation for providing the additional care of a qualified foster individual which is —

Shirley and Donzetta began their Lifesharing in 1996, after knowing each other for nine years. Despite misgivings about her ability to drive to Washington, Shirley and Donzetta did just that. There they met the other families from Oklahoma, Nebraska and South Dakota, and set about keeping the many appointments with Senators and Representatives – to clarify the age of the people with disabilities receiving caregiving and the tax exemption available. It was an exhausting schedule and much of the time they received only cursory recognition, but typically, the Congressman or aide gave them a business card, so Donzetta began asking everyone for cards from the start. She was not shy with anyone – and ended up having a ball. They took one day for sightseeing, but otherwise it was a week of very hard work. They arrived home to discover they both had blisters on their feet.

Much time went by with no word. But finally, Shirley heard from a friend that they had succeeded. On March 9, 2202, the bill that said, "...regardless of age of person receiving care, regardless of whether the money is paid by a state or private agency...", was signed by President Bush.

from Pennsylvania Lifesharing Newsletter

- (i) required by reason of a physical, mental, or emotional handicap of such individual with respect to which the State has determined that there is a need for additional compensation, and
- (ii) provided in the home of the foster care provider..."

In order to qualify for a difficulty of care tax exemption, the placement must be made by a qualified agency to a qualified provider. The 2002 Job Creation and Worker Assistance Act made changes to regulations governing foster care payments by redefining what constitutes a qualified foster care placement agency and by permitting providers to qualify for the tax exemption regardless of the age of the individual being placed.

In the past, the definition of qualified agency was more restrictive;

⁴⁵ "Medicaid Home and Community-Based Services for Persons with Intellectual and Developmental Disabilities: Background and Findings from Consumer Interviews and the Medicaid Statistical Information Systems, Final Report," (Prepared for: Centers for Medicare & Medicaid Services, Submitted by: The University of Minnesota Research and Training Center on Community Living, September 2006), p.vii, <http://rtc.umn.edu/docs/HCBSFinalrprt.pdf>.

consequently, some placements made by counties – or other entities authorized by the state to make placement – were not considered qualified agencies. With the 2002 changes, "The term 'qualified foster care placement agency' means any placement agency which is licensed or certified by —

(A) a State or political subdivision thereof, or

(B) an entity designated by a State or political subdivision thereof, for the foster care program of such State or political subdivision to make foster care payments to providers of foster care."⁴⁶

This change in what constitutes a qualified placement agency allows placements made by counties, or contracted entities (such as the California regional centers or the Colorado community centered boards) to qualify for the difficulty of care tax exemption. In concert with opening up the definition of qualified placement agency, the 2002 rules also expanded the definition of a qualified foster care *payment* to mean any disbursement made by a state, political subdivisions, or a qualified placement agency.

Previously the tax exclusion only applied if the individual supported was under the age of 19. The new regulations have no mention of the age of the person in the qualified placement, thus adults are clearly also covered under this tax exemption. Although this is good news, there are some limitations on the use of the tax exemption. While the situation does not require licensing or certification – the qualified placement *must occur in the home of the provider*. Hence, situations where an individual with a disability shares his or her own home or apartment with the person providing support will not qualify for the tax exemption. Also, any room and board paid to the provider cannot be claimed as a deduction and must be reported as income. Additionally, in August 2003, the IRS wrote a memorandum that clearly indicates that payments to respite providers who work in the foster home are not tax exempt.⁴⁷ Since the qualified placement agency does not make the respite placement and the payment is considered by the IRS as payment for "services rendered," it does not qualify as a difficulty of care payment and accordingly is not excludable from taxable income.

More and more families are providing care to their own family members and, in particular, parents are providing care to both adult and minor children.⁴⁸ Recently a state asked the IRS for an opinion about a situation where a parent provided paid care to an adult daughter. The IRS responded,

"In general, compensation for services is included in gross income [section 61(a) (1) of the Internal Revenue Code (the Code)]. In *Bannon v.*

⁴⁶ H.R. 3090 [107th]: Job Creation and Worker Assistance Act of 2002, SEC. 404. EXCLUSION FOR FOSTER CARE PAYMENTS TO APPLY TO PAYMENTS BY QUALIFIED PLACEMENT AGENCIES. a. (1)(A).

⁴⁷ See Appendix C containing the full IRS ruling on respite payments.

⁴⁸ In 2010, six states paid the parents of minor children to provide care and 36 states paid the parents of adults to provide care under the HCBS waiver. Noted in "*Caring Families, Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities*", Robin Cooper, NASDDDS, June 2010, p.9.

Commissioner, 99 T.C. 59 (1992), a mother received payments for the care of her adult disabled daughter through a state program to provide supportive services to disabled adults living at home. Although the payments were not taxable to the daughter, the tax court held that the payments were taxable to the mother as compensation for services and that the law did not provide an exclusion for the payments.

Certain payments to a foster care provider, including any "difficulty of care payments," are excluded from gross income (section 131 of the Code). Difficulty of care payments are defined, in part, as compensation for the additional care of a qualified foster individual that the state determines is necessary by reason of the individual's physical, mental, or emotional handicap. Section 131 applies only to payments for foster care, not to the care of a child by a parent. Congress would need to enact legislation to exclude from gross income payments that a parent receives for providing care to a disabled child."⁴⁹

It seems that, even if the home is licensed as a foster care setting, and the payment made by a qualified agency, the IRS still does not view the payment to be tax deductible. However, the case cited by the IRS was in 1992, before the 2002 changes to the rules. Given the changes in what constitutes a qualified placing agency and payment, NASDDDS has contacted the IRS for affirmation of this ruling. As of the date of publication, we have not received a reply.

Shared Living in the Individual's Own or Mutually Shared Home

Unpaid Arrangements

The simplest option of shared living is that two individuals choose to live together as roommates with no expectation of payment for supports offered. This is a mutually agreed upon, mutually satisfying relationship that requires no financing – it is fully a choice of the individuals with no regard to payment of any kind. Clearly if the individual has a guardian, it is appropriate that the guardian be involved, but the state has no official say in these arrangements and plays a role only at the invitation of the persons involved. Sometimes siblings or long-time friends opt for this arrangement. Certainly it makes sense to offer assistance through the provision of supports such as case management, access to employment and other such consultation as might facilitate the continuation of the relationship. But since this is a "private" relationship, the official responsibility of the state would be determined through the individual planning process and would most likely govern only the specific services funded by the state agency. However, as with all individuals known to the state service system, states must be ready to assist should the arrangement become problematic and no longer helpful for the person with a disability.

⁴⁹ Letter to NH Representative Paul W. Hodes, Department of the Treasury, Internal Revenue Service, Number: INFO 2009-0230, Release Date: 12/31/2009, UIL: 61.00-00 CONEX-145781-09, Michael J. Montemurro, Chief, Branch 4, Office of Associate Chief Counsel (Income Tax & Accounting).

If issues arise such as questions of abuse or neglect, the state will then have an official role in the living arrangement. In **New York**, Onondaga Community Living has worked with individuals to create shared living relationships in which the person providing support is not paid. Sometimes the arrangements include rent subsidies – and the person with a disability may receive other paid supports – but there is no payment for service to the person who lives with the individual with a disability.

Live-In Caregiver Option Under the HCBS Waiver

In 1990, the HCBS waiver statutes were amended to permit states to pay the room and board costs of an *unrelated* personal caregiver who lives with the HCBS waiver participant.⁵⁰

The payment may be made for, "...a portion of the rent and food that may be reasonably attributed to the unrelated caregiver who resides in the same household with the waiver recipient. FFP for a live-in caregiver is *not* available if the recipient lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services (the caregiver)."⁵¹

As described in the Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, in order to take advantage of this option, the state must apply for this authority in their HCBS waiver.⁵²

To gain approval for this option states must:

- Establish personal caregiving as a waiver service;
- Provide a methodology for calculating the live-in caregiver payments; and

"I was talking with a woman who is the nondisabled housemate to someone that we support. She lives there freely as a companion and friend and is not in any paid or volunteer role. These two women have lived together over the last few years....Although her housemate is classified as severely intellectually disabled, this woman has become to know her as a very intelligent peer. They have a wonderful home and work together to share the responsibilities of not only their home but also their interdependent lives. As I was on the phone with her the other day, I realized that her role from teacher to learner had occurred... She also shared with me the times that they have had in growing together through times of struggle. As she has gotten to know her life sharing partner more fully she has learned much about her own self along the way. She remarked that she felt she was a part of such a wonderful arrangement, that her housemate was such a lovely person and that she felt so fortunate to have been brought together."

Pat Fratangelo, "Sharing Lives," TASH Connections, September/October 2006, p.9

⁵⁰ Section 4741(a) of the Omnibus Budget Reconciliation Act of 1990 amended §1915(c)(1) of the Social Security Act.

⁵¹ 42 CFR §441.310(a) (2) (ii).

⁵² "Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria," (Release Date, January 2008), p.266-267.

- Set up a payment system whereby the payment is made to the provider and then paid to the waiver recipient who has incurred the live-in caregiver room and board costs.

This last step is important in order that the payment be made as a reimbursement for incurred expenses and not as income to the waiver participant – since this could affect other benefits. The projected utilization and costs of the live-in caregiver option must be reflected in Appendix J of the waiver application that lays out the annual cost projections for the waiver.

As an example, the **Connecticut** Department of Developmental Services (DDS) has an approved live-in caregiver service in their HCBS waiver serving individuals with intellectual disabilities:

"DDS reimburses the waiver participant for the cost of the additional living space and increased utility costs required to afford the live-in caregiver a private bedroom. The reimbursement for the increased rental costs will be based on the DDS Rent Subsidy Guidelines and will follow the limits established in those guidelines for rental costs.⁵³ The reimbursement for food costs will be based on the USDA Moderate Food Plan Cost averages. Payment will not be made when the participant lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services."⁵⁴

Indiana, Minnesota, New York, Virginia, and Maryland also offer the live-in caregiver option.⁵⁵

Companion Services

Another option for financing shared living is the use of a companion service. While more common in programs serving seniors, companion services may be an option that works well for individuals who do not need substantial hands-on supports and whose companion does not need extensive support and supervision. As with the live-in caregiver option, states may cover companion services under a HCBS waiver program. Companion services are defined by CMS as:

"Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the participant with such tasks as meal preparation, laundry and shopping. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks that are incidental to the care and supervision of the

⁵³ Information on Connecticut's' rent subsidy may be found at http://www.ct.gov/dds/lib/dds/dds_manual/ic_housing/i_c_pr_002_housing_subsidy.pdf.

⁵⁴ Additional information on Connecticut's Live-In Companion option may be found at <http://www.ct.gov/dds/cwp/view.asp?a=2042&q=442624>.

⁵⁵ New York's approved HCBS waiver Live-in Caregiver option can be found in Appendix B.

participant. This service is provided in accordance with a therapeutic goal in the service plan".⁵⁶

CMS additionally instructs states that they can modify the definition to reflect the exact array of supports provided under the companion service. But CMS does caution states that cover other similar services, such as personal care or chore/homemaker services, to provide assurances that the companion service will not duplicate these other services. Typically this means a state needs to indicate that companion services and chore or personal care services are not billed concurrently if the definitions of the services overlap. While companion services often are intermittent, the companion could potentially live with the individual and provide supports on a paid basis as established by the individual plan of care.

Personal Care

States have several options to finance personal care services. Personal care may be covered under the Medicaid State plan as an optional service. The HCBS waiver offers states the authority to provide personal care. And there are several new authorities under the state plan, including 1915(i), 1915(j), and 1915(k), that offer coverage of personal care services. (See Appendix A for a brief description of these authorities.)

In particular the HCBS waiver offers states the opportunity to craft their own definitions of personal care. In these definitions, supports do not have to be restricted to hands-on assistance. Many states have redefined and renamed personal care, expanding the definition to include support, supervision, training and companionship. For example, in the early 1980s Wisconsin redefined personal care by expanding the traditional definition to include other than hands-on assistance. Called Supportive Home Care Services, personal care now includes: "Supporting and monitoring participants in their home, while being transported and in community settings..." – i.e., accompanying people to community activities, support with medications, help with carrying out therapies, and household assistance with chores.⁵⁷ This type of broad-based, redefined personal care option can easily be used to support shared living.

Residential Habilitation/Supported Living

Under the HCBS waiver and the 1915(i) and 1915(k) options, states can provide in-home supports. The HCBS waiver offers a category called "Residential Habilitation" that can include supported living-type services. But states have broad flexibility – thus some states only include provider owned settings under residential habilitation, separating out other services that occur in the person's own home. Called community living supports,

⁵⁶ "Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria," (Release Date, January 2008), p.171.

⁵⁷ Supportive home care definition is taken from Wisconsin's Application for a 1915(c) HCBS Waiver Number 0229, called CIP I which serves adults with developmental disabilities. State waiver applications can be found at <http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp>.

supported living, personal supports, etc., these are well-established services that every state covers.

Using residential habilitation or supported living to finance shared living is really a matter of program design rather than service definition. Supported living often encompasses come-in staff that may not be the same every day and this would not be compatible with the definition of shared living. But supported living or residential habilitation that promotes individuals sharing their home with the individual providing support clearly is shared living. Shared living is not a matter of service title – rather it is an approach to designing a living arrangement and supporting the individuals involved to have a mutual, supportive relationship.

Participant-Directed Options

Some of the financing options described above such as personal care and supported living can be delivered under a consumer-directed model. (Host home/foster care cannot because it is considered a "provider-controlled" setting and thus not amenable to consumer-directed options other than the freedom of choice to live with someone.) In a consumer-directed model, the person providing support is an employee. And, in some cases the person providing support may be the employee of a representative, not of the individual supported. The complexities of the consumer-directed model need to be addressed in order to preserve the mutuality of a shared living relationship. While in all shared living arrangements the individual being supported should have the ultimate say about how they are supported, honestly addressing the roles and responsibilities of an employer-employee relationship in the context of shared living may be worthwhile to assure the mutuality of the relationship.

Massachusetts offers an option under their adult residential waiver called "Self-Directed 24 Hour Support". They are in the process of making an amendment to the program to include a service entitled, "Shared Living No Agency." As with many new services, Massachusetts reports, this new service has come about because families have identified care providers on their own and want to be fully involved in self-direction. In essence the families do the matching, recruiting, and training. The payment to the care provider is through the fiscal Intermediary. Massachusetts estimates that they have approximately 50 or so of these arrangements and that "Shared Living No Agency" is another viable option because it combines both the sharing of lives and the supporting of participant direction, along with providing great comfort to the birth family.

Beyond the shared living arrangement, consumer-direction can be employed for other services such as employment and companion services. An individual budget for the additional support services beyond the shared living arrangement, with the authority to choose a provider, could provide an individual with considerable choice and control. The consumer would likely confer with the shared living provider about his or her choices.

Chapter 4:

Identifying and Managing the Risks of Shared Living

Shared living offers a very positive and satisfying option for some individuals. But sharing lives comes with its own set of risks and liabilities. Not all relationships work over the long-term. Even with the best intentions and good planning, relationships can, and do, fail. As part of the person-centered planning process – both initially and ongoing – it is essential to identify the potential disadvantages of shared living as well as the specific risks and issues for each particular situation.

Moving Into Someone Else's Home

The match is often not just one-to-one. The individual supported may be moving into an established household with other members. In order for this arrangement to work, the match must be made among everyone – not just between the person supported and the identified person providing supports. **Pennsylvania** and **Georgia** (among others) conduct a very detailed home study that reviews all individuals in the home. The home study looks at the motivation of the provider along with other information such as descriptions of the personalities of household members. This type of deep knowledge of the situation is critical for matching individuals. If the household is a quiet, contemplative home and the person supported is an outgoing highly social individual who enjoys lots of company, a successful match will be unlikely. Understanding the dynamics of the "host" family and matching those characteristics to the person supported is pivotal to success.

Georgia Home Study Requirements

Family Dynamics:

- (a) Interest and hobbies (include clubs, groups, associations etc.)
- (b) Personality of each member of the household
- (c) Interaction and relationship with neighbors
- (d) Examples of ways each person in household tend to interact with others in the home
- (e) Examples of ways each family member react to stress and coping strategies used
- (f) Family meal-time interaction (include what meals family eat together if applicable)
- (g) Family activities after work/school to bedtime
- (h) Description of a typical Saturday, Sunday, holiday, and vacations
- (i) Church or other religious relationship
- (j) Acceptance of an individual(s) of another culture/ethnicity. (Include response to various cultural issues i.e. religious practices, eating habits, holiday traditions)
- (k) Attitudes on potential placement(s) dating
- (l) Alcohol or drug use in the family (Include history and where alcohol is stored)
- (m) Anticipated adjustment of each life sharing member to a potential placement

"Host/Life-Sharing Home Guidelines," p.7

Ascertaining how families deal with stress or their style for solving conflicts, although touchy areas to discuss, may provide information critical for predicting the success of the match. Another subject that often does not receive enough attention is dating and sexual relationships. Frank and open discussion is very important in order to establish everyone's comfort level – and an understanding of everyone's rights. (But exceptions always make for interesting additions to the rules: see "Georgia Home Study Requirements" on previous page.)

... I'm not going to lie; when my parents explained the program to me I was very apprehensive. Imagine a stranger coming to live in your house and becoming a part of your family. My parents described the program as a "rewarding new experience," I thought of it as a major inconvenience and interference. My house is complicated enough with all of my brothers and sisters never mind adding a person with a developmental disability to the picture...

I know, I sound mean right? Who wouldn't want to help someone out? Well I didn't, at least not at first.

... That was until Jenn told me about her parents and how they went on vacation or ran off into the woods. She explained that there was no more mommy and daddy and that her house is all broken down. She told me she liked the new house and the new shower and toothbrush. She explained that she wanted to sleep over Monday, Wednesday, Thursday, Tuesday, Friday, Saturday and Sunday. I told her that she could stay as long as she wanted to...

... For the first time in my life I feel as though I have directly impacted someone's life and helped them. My family and I have provided Jenn with more than just a place to live and a toothbrush but we have given her a sense of family, something that she never had and something that I took for granted. My parents were right... Jenn is a part of my family. Jenn is my sister.

from 2009 College Application Essay - The author's parents are mentors with Rhode Island MENTOR's Shared Living Program

How family members view the inclusion of another person in the household needs to be addressed. Simply assuming that everything is fine with other family members may lead to unanticipated problems. In-depth interviews – which require spending significant time with the host family members in order to get to know them – will likely result in a better match and outcome. This is all the more important because if the living arrangement does not work, the person being supported would have to move – which is stressful and disruptive.

Isolation and Dependency

In some instances, shared living can result in limiting an individual's options and exposure to activities outside of the home. Some homes may be in rural areas, or in suburban areas with more limited access to transportation or community activities (like shops, restaurants and theaters). Thus the individual may be fully dependent on the provider to assist in gaining access to experiences and

activities and may find themselves limited to the activities the provider typically engages in.

Also, in some shared living situations, as **Vermont's** guideline cautions, "There may be fewer independent or external eyes on the person." As John O'Brien has pointed out,

part of what makes us safe in our community is being "known" to others.⁵⁸ The more relationships we have, the more likely it is for someone to notice that we haven't shown up somewhere, or that we don't look well. Isolation is both a social issue and a safety issue. Thus planned attention to the range of social and community activities, both with and without the shared living provider, can mitigate some of the concerns around dependency and isolation.

Losing the Voice of the Person

In shared living, as with any of the ways individuals with disabilities are supported, attention must actively be paid to the person supported. There is a risk that the person providing support might become the voice for the individual. The intimacy of the shared living situation can result in others relying on the voice of the person providing support, forgetting to actively attend to the person being supported. In assessing the quality and outcomes of the arrangement, it is important to build in opportunities to hear from the individual being supported. This can be done through meeting with them privately to hear any potential concerns or by meeting with others of the supported person's choosing who can help them express their concerns.

Because in many instances there is a fiduciary relationship between the life sharing provider and the individual – no different from other paid support situations – some vigilance is advised to assure that the financial needs of the provider do not compromise the arrangement and that the voice of the individual supported is the most salient one in making decisions about the arrangement.

Self-advocacy training and participation in support groups can strengthen the voice of the person with a disability.

Moving On

Vermont's guidelines note, "People and agencies may become comfortable with this [shared living] option. It can therefore be programmatically, emotionally, and fiscally challenging for people to "graduate" out of shared living to more independent supervised living." While one of the benefits of shared living can be the longevity and stability of the relationship, individuals do grow and change. The needs of the person supported may change over time – he or she may come to need more support as he ages, or he may come to require less support as he grows in independence. Or, as with any housemates, the person may simply at some point have a desire to live with someone else. The needs of the provider may change as well. A willingness to open the situation to discussion and review as part of the person-centered planning process is therefore highly recommended. Reaffirming the relationship and a commitment to continue the arrangement could be a formal part of the annual review of the situation.

⁵⁸ See John O'Brien and Connie Lyle O'Brien, *Assistance with Integrity: The Search for Accountability and the lives of People with Developmental Disabilities*, (Responsive System Associates, 1993), <http://thechp.syr.edu/integri.pdf>.

Effective Safeguards: A Recap

The quality of shared living rests on more than the processes and procedures – the standards, training, etc. – of formal quality compliance and assurance. Shared living also depends on other safeguards such as:

Being known: As John O'Brien has said, "...being known to others is the greatest safeguard." Shared living opens up possibilities for relationships with many people beyond those paid to provide support. This wider network of friends and acquaintances increases the likelihood that problems will be identified and addressed. Building this network is, of course, more likely when one is aware of the benefits of such a network and so spurred to focus attention on the development of relationships beyond those with paid care givers. What O'Brien calls "effective interdependence" is a means to assure accountability for quality, safety and outcomes in the lives of individuals with intellectual disabilities.⁵⁹

Self-advocacy training and participation in self-advocacy groups is empowering and provides people with the skill to speak up for themselves.

Robust person-centered planning: Person-centered planning has been a part of our service system lingo since the early 1980s. But true person-centered planning is a commitment to much more than the planning process – it is a way of doing business throughout the system. Person-centered planning can only really occur in a person-centered system...thus commitment to person-centered planning means a commitment to a person-centered system. The recent experiences of six states who embarked on a journey to person-centered systems is instructive (see the pieces named in the footnote) – and can act as a guide in person-centered planning efforts.⁶⁰

Competent, well-resourced case management and shared living coordination: Lastly, the role of the case manager and the shared living coordinator are crucial to minimizing risk. Frequent and casual communication with the consumer as well as the shared living provider increases trust and openness. The consumer and the shared living provider must each know that they can tell the coordinator or case manager if there are problems and if they need assistance.

⁵⁹ O'Brien, 1993, p.16-30.

⁶⁰ See Michael W. Smull, Mary Lou Bourne, and Helen Sanderson, "*Becoming a Person Centered System-A Brief Overview*," (April 2009) and "*Best Practice, Expected Practice, and the Challenge of Scale*," (April 2010).

Parting thoughts...

So, what is shared living really about? It is about the mutuality of a shared life, while clearly assuring the autonomy and individuality of the individual being supported. It is about a real relationship.

A very short story says quite a bit:

Late one evening Michael's mom and dad found voicemail messages on their cell and house phones. The call was from Michael's phone number so they called back immediately.

Antoinette, Michael's shared living partner answered the phone. "Michael got a job this morning," she said, "and we were so excited – we were calling everyone all night to tell them the good news."

She said, "**We** were so excited, **we** were calling everyone..."

It's all about the "**we**"...

Appendices

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Authority Type	Waiver	State plan option	State plan option	State plan option	Secretarial waiver
Effective Date	1981	Original: January 1, 2007 Revised: October 1, 2010	January 1, 2007	October 1, 2011	1990
Purpose	Provides Home and Community-Based (HCBS) Services to individuals meeting income, resource, and medical (and associated) criteria who would otherwise be eligible to reside in an institution.	Provides HCBS to individuals who require less than institutional level of care and who would therefore not be eligible for HCBS under 1915(c). May also provide services to individuals who meet the institutional level of care.	Provides a new State Plan participant-directed option to individuals otherwise eligible for State Plan Personal Care or 1915(c) services.	Provides a new State plan option to provide consumer controlled home and community-based attendant services and supports Provides a 6% FMAP increase for this option	Authorizes the DHHS Secretary to consider and approve experimental, pilot or demonstration projects likely to assist in promoting the objectives of the Medicaid statute.
Requirements That May Be Waived	<ul style="list-style-type: none"> Statewideness Comparability Community income rules for medically needy population 	<ul style="list-style-type: none"> Statewideness Comparability Community income rules for medically needy population 	<ul style="list-style-type: none"> Statewideness Comparability 	Community income rules for medically needy population	Secretary may waive multiple requirements under 1902 of the Social Security Act if waivers promote the objectives of the Medicaid law and intent of the program.

		Comparative Analysis of Medicaid State Plan Waivers & Amendments			
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Application Process	Application submitted electronically via 1915(c) HCBS waiver application	State plan amendment submitted on pre-print.	State plan amendment submitted on pre-print.	State plan amendment submitted on pre-print	No standardized application format. Requires approval of an Operations Protocol within 90 days of operation. Must be approved by CMS and an External Federal Review Team; CMS readiness review site visit required
Approval Duration	Initial application: 3 years Renewal: 5 years	One-time approval. Changes must be submitted to CMS and approved. <i>If using targeting, renewal every 5 years.</i>	One-time approval. Changes must be submitted to CMS and approved.	One-time approval. Changes must be submitted to CMS and approved.	Initial application: 5 years Renewal: 5 years
Reporting	Annual reports.	Annual reports.	Annual reports and triennial health and welfare reports required.	Annual reports on expenditures and utilization and quality measures	Monthly progress calls, quarterly and annual progress reports.

APPENDIX A
HHSM-500-2006-00006I
Task Order 0009

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Administration & Operation	Administered by the Single State Medicaid Agency (SSMA). May be operated by another state agency under an interagency agreement or memorandum of understanding.	Administered by the Single State Medicaid Agency (SSMA). May be operated by another state agency under an interagency agreement or memorandum of understanding.	Administered by the Single State Medicaid Agency (SSMA).	Administered by the Single State Medicaid Agency (SSMA). Unclear about operation by another State agency under MOU.	Administered by the Single State Medicaid Agency (SSMA). May be operated by other entities as approved by CMS.
Provider Agreements	Required between providers and the SSMA. Delegation allowed to a provider agency under the Organized Health Care Delivery System or Provider of Financial Management Services. Requires written specification of delegated activity.	Required between providers and the SSMA. Delegation allowed to a provider agency under the Organized Health Care Delivery System or Provider of Financial Management Services. Requires written specification of delegated activity.	Required between providers and the SSMA. Delegation allowed to a provider agency under the Organized Health Care Delivery System or Provider of Financial Management Services. Requires written specification of delegated activity.	Required between providers and the SSMA. Unclear about OHCDS	Not required.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Medicaid Eligibility	May use institutional income and resource rules for the medically needy (institutional deeming). May include the special income group of individuals with income up to 300% of SSI.	<i>All individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level. May include special income group of individuals with income up to 300% SSI. Individuals must be eligible for HCBS under a 1915(c), (d), or (e) waiver or 1115 demonstration program.</i>	Must be Medicaid eligible for and receiving services under either state plan requirements or eligible for and receiving services under a 1915(c) HCBS waiver	Individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level. Individuals with income greater than 150 % of the FPL may use the institutional deeming rules.	State defines eligible categories and may expand eligibility. Not intended to add new Medicaid eligibility group(s).
Other Eligibility Criteria	Must meet institutional level of care.	<i>For the 300% of SSI income group, must be eligible for HCBS under a 1915(c), (d), or (e) waiver or 1115 demonstration program.</i>		May include the special income group and receiving at least one home and community-based waiver service per month.	State determines requirements for services.

		Comparative Analysis of Medicaid State Plan Waivers & Amendments			
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Target Groups	<ul style="list-style-type: none"> Aged or disabled Mentally retarded or developmentally disabled Mentally ill (ages 22-64) Any subgroup of the above 	<i>May define and limit the target group(s) served</i>	May define and limit the target group(s) served.		State determines target groups and defines eligibility criteria.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Other Unique Requirements	None.	<i>Multiple State plan amendments covering different target groups permitted.</i>	Must either operate a HCBS waiver covering PAS or have an approved state plan amendment for "traditional" PAS.	MOE requirement for 1 st fiscal year for services provided under sections 1115, 1905(a), and 1915, of the Act Must establish and consult with a Development and Implementation Council Cannot cover: Certain assistive devices and assistive technology services; Medical supplies and equipment. Home modifications. Increased FMAP Section 1915(k)(2) of the Act provides that States offering this option to eligible individuals during a fiscal year quarter occurring on or after October 1,2011 will be eligible for a 6 percentage point increase in the Federal medical assistance percentage (FMAP)	State must operate under an approved Operations Protocol.

		Comparative Analysis of Medicaid State Plan Waivers & Amendments			
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services (ACA new requirements in <i>bold italics</i>)	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Limits on Numbers Served	Allowed.	Not allowed.	Allowed.	Not allowed.	State estimates numbers served. Operates as an entitlement to all who are eligible.
Waiting Lists	Allowed.	Not allowed.	Allowed.	Not allowed.	Not applicable.
Combining Service Populations	Combining service populations is limited to: 1) Aged/Disabled 2) Mentally Retarded or Developmentally Disabled 3) Mentally Ill 4) Any subgroup of the above	States may combine service populations.	States may combine service populations.	States may combine service populations	States may combine service populations.
Caps on Individual Resource Allocations or Budgets	Allowed.	May determine process for setting individual budgets for participant-directed services.	May determine process for setting individual budgets for participant- directed services.	May determine process for setting individual budgets for participant-directed services.	Budget neutrality must be maintained. Caps or benefit limits may apply.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Allowable Services	<ul style="list-style-type: none"> Case management services Homemaker/home health aide services and personal care services Adult day health services Habilitation services Respite care "Other services requested by the State as the Secretary may approve" Day treatment or other partial hospitalization services* Psychosocial rehabilitation services* Clinic services* <p>* For individuals with chronic mental illness</p>	<p><i>Includes both 1915(c) statutory services and "other" category of services.</i></p>	<ul style="list-style-type: none"> Personal care or related services. Home and community-based services otherwise available to the participant under the state plan or an approved 1915(c) waiver. At state's discretion, items that increase an individual's independence or substitute for human assistance. 	<p>MUST COVER:</p> <ul style="list-style-type: none"> Assistance with ADLs, IADLs, and health related tasks. Acquisition, maintenance and enhancement of skills necessary for the individual to accomplish ADLs, IADLs, and health-related tasks. Back-up systems or mechanisms to ensure continuity of services and supports. Voluntary training on how to select, manage, and dismiss staff. <p>MAY COVER</p> <ul style="list-style-type: none"> Transition costs Expenditures relating to a participant's independence or substitute for human assistance, Services and supports that are linked to an assessed need or goal 	<p>State decides what services are covered, subject to CMS approval.</p>

Prepared by: R. Cooper

Re-edited by R. Cooper, 4/6/11

APPENDIX A
HHSM-500-2006-00006I
Task Order 0009

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Provider Qualifications	Determined by state, subject to CMS approval.	Determined by state, subject to CMS approval.	No statement required as to provider qualifications in the 1915(j) preprint.	Determined by state, subject to CMS approval.	Determined by state, subject to CMS approval.
Participant- Directed Services	Allowed.	Allowed.	Required.	Required	Allowed.
Hiring of Legally Responsible Individuals	Allowed.	Allowed.	Allowed.	Not allowed for personal care services	Allowed.
Cash Payments to Participants	Direct cash payments not permitted.	Direct cash payment not permitted.	Direct cash payments are permitted.	Direct cash payments are permitted	Direct cash payments are permitted.
Financial Management Services	Required if participant direction is offered. May be a waiver service, an administrative function, or performed directly by the SSMA.	Required if participant direction is offered. May be provided by SSMA mechanism or as an administrative service. Service reimbursement is not available.	Required. May be provided by SSMA mechanism or as an administrative service. Service reimbursement is not available.	Required depending on model of participant direction.	Required if participant direction is offered. May be a demonstration service or an administrative function.
Goods and Services	Permitted as a wavier service.	<i>Permitted as a service.</i>	Permitted as a service.	Permitted as a service.	Permitted as a service.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Direct Payment of Providers	Required (state has options to meet this requirement).	Required.	Required.		Not required.
Provider Payments	Payment item must be listed in the service plan (plan of care), provided by an enrolled provider, and provided prior to reimbursement.	Payment item must be listed in the service plan (plan of care), provided by an enrolled provider, and provided prior to reimbursement.	Payment item must be listed in the service plan (plan of care), provided by an enrolled provider, and provided prior to reimbursement.	Payment item must be listed in the service plan (plan of care), provided by an enrolled provider, and provided prior to reimbursement.	Payments for allowable services may be paid prospectively (before the service is provided)
Cost Requirements	Must be cost-effective. Average annual cost per person served under 1915(c) cannot exceed average annual cost of institutional care for each target group served.	None. Benefit limits may apply.	None. Benefit limits may apply.	None. Benefit limits may apply. For the first full fiscal year in which the State Plan amendment is implemented, a State must maintain, or exceed, the level of expenditures for services provided under sections 1115, 1905(a), and 1915, of the Act, or otherwise to individuals with disabilities or elderly individuals attributable to the preceding fiscal year.	Budget-neutrality. Services cannot in aggregate cost more than without the 1115 waiver.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Quality Management	Extensive quality management and quality improvement activities required per HCBS Waiver Application, including how state will comply with all multiple waiver assurances and how state will conduct quality oversight, monitoring and discovery, remediation and improvement of issues relating to quality.	Pre-print requires a quality assurance and improvement plan including how state conducts discovery, remediation and quality improvement.	Requires a quality assurance and improvement plan including how state conducts discovery, remediation and quality improvement. State must provide system performance measures, outcome measures, and satisfaction measures that will be monitored and evaluated.	Requires a quality assurance and improvement plan including how state conducts discovery, remediation and quality improvement. State must provide system performance measures, outcome measures, and satisfaction measures that will be monitored and evaluated.	Extensive data collection and evaluation plans to assess the effectiveness of the project or demonstration.

Comparative Analysis of Medicaid State Plan Waivers & Amendments					
Features	1915(c) Home and Community- Based Services Waiver	1915(i) State Plan Home and Community Based Services <i>(ACA new requirements in bold italics)</i>	1915(j) Self Directed Personal Assistance Services (PAS)	1915(k) Community First Choice Option (N.B.:Material excerpted from PROPOSED regulations)	1115 Research and Demonstration Projects
Interaction with State Plan Services, Waivers, & Amendments	Participants have access to and must utilize state plan services before using identical extended state plan services under the waiver. Waiver services may not duplicate state plan services. Individuals may be eligible for and receive State plan, 1915(c), 1915(i) and 1915(j) services simultaneously.	Individuals may be eligible for and receive State plan services, 1915(c), 1915(i) and 1915(j) services simultaneously, so long as the service plan (plan of care) ensures duplication of services is not occurring.	State must either operate a HCBS waiver covering PAS or have an approved state plan amendment for "traditional" PAS. Individuals voluntarily or involuntarily dis-enrolled from 1915(j) must have access to other PAS services under the state plan or 1915(c). Individuals may be eligible for and receive State plan, 1915(c), 1915(i) and 1915(j) services simultaneously.	Individuals may be eligible for and receive State plan, 1915(c), 1915(i) and 1915(j) services simultaneously.	State defines relationship to state plan, waivers, and amendments, subject to CMS approval.

Appendix B

NY Comprehensive Waiver renewal 0238 October 1, 2009

NY Live-in Caregiver service definition

Live-in Caregiver is an unrelated care provider who resides in the same household as the waiver participant and provides as needed supports to address the participant's physical, social, or emotional needs in order for the participant to live safely and successfully in his or her own home. The Live-in Caregiver must be unrelated to the participant by blood or marriage to any degree.

Payment for this service will cover the additional costs of room and board incurred by the waiver participant that can be reasonably attributed to the live-in caregiver. Room and board includes rent, utilities and food. The method for determining the amount paid is specified in Appendix I-6.

Payment will not be made directly to the live-in caregiver. Payment will be made to a provider agency that will in turn transfer the appropriate amount of funds to the participant.

The participant must reside in their own home or leased residence. Payment will not be made when the participant lives in the caregiver's home, in a residence that is owned or leased by the provider of Medicaid services, in a Family Care home, or any other residential arrangement where the participant is not directly responsible for the residence.

The need for Live-in Caregiver will be documented in the participant's plan of care.

Appendix I

OMRDD staff (DDSOs) conduct a fair market appraisal for the monthly rent of the apartment to be leased by the service recipient, noting actual bedrooms vs. needed bedrooms and whether the lease is a related party transaction. The district office staff determines what if any, other benefits such as HUD subsidy, HEAP or food stamps the service recipient may be eligible to receive. These benefits are deducted from the household costs for rent, food and utilities prior to calculating costs associated with the live-in caregiver as follows:

The lesser of the actual rent or fair market rent is divided by the actual number of bedrooms to determine the portion of monthly rent associated with the live-in caregiver. Annual food and utility costs are estimated for the household, reviewed for reasonableness by district office staff, and divided by, the number of persons residing in the household times twelve months, to determine the amount associated with the live-in caregiver. Payment of the total calculated monthly amount associated with the live-in caregiver is made directly to the service recipient each month.

If the lease is a related party transaction, total payment for the portion of rent attributable to the live-in caregiver is further limited to the landlord's actual cost of ownership.

Appendix B

If the service recipient owns their own home and is making mortgage payments, the aforementioned process shall be used, substituting the annual interest paid on the mortgage in lieu of the rental amount. If there is no mortgage, reimbursement associated with the live-in caregiver will be limited to the pro- rated share of utilities and food only.

APPENDIX C

APPENDIX C: IRS Ruling on Respite Care Providers

NOVEMBER 24, 2003 MONDAY

DEPARTMENT: Administrative Rulings; IRS Legal Memorandums

CITE: 2003 TNT 226-19

LENGTH: 3198 words

HEADLINE: 2003 TNT 226-19 PAYMENTS TO RESPITE CARE PROVIDERS AREN'T EXCLUDABLE FROM INCOME. (Section 131 -- Foster Care Payments;) (ILM 200347004) (Release Date: AUGUST 06, 2003) (Doc 2003-24974 (7 original pages))

CODE: *Section 131* -- Foster Care Payments;
Section 3401 -- Income Tax Withholding

ABSTRACT: In a legal memorandum, the Service has rendered advice on issues related to respite care providers, concluding in part that the providers' payments aren't excludable from gross income.

SUMMARY:

Published by Tax AnalystsTM

In a legal memorandum, the Service has rendered advice on issues related to respite care providers, concluding in part that the providers' payments aren't excludable from gross income.

Respite care workers provide services to foster care providers to temporarily relieve them of their foster care responsibilities. Regardless of whether respite care providers are certified by the states as qualified foster care providers, the government agencies make direct payments to the respite care providers. Foster care providers may request specific respite workers, and respite workers can refuse to provide services based on length of stay or other circumstances.

The Service advised that respite care payments aren't excludable from income because the requirements of *section 131(b)(1)(B)* and *131(b)(2)* aren't satisfied. Specifically, a governmental agency or qualified foster care placement agency doesn't place the individual in foster care with the respite care provider. Further, the payment to the respite worker is a payment for services, not a payment to cover the costs of care or a difficulty-of-care payment. Hence, the respite workers' payments are income under *section 61*.

The Service noted that it didn't have enough information to determine whether a respite worker is an independent contractor or a common law employee. However, the Service advised that if the government agency isn't the common law employer, the agency is

APPENDIX C

considered to be the *section 3401(d)(1)* employer because the agency controls the payment of wages to the respite worker. As the *section 3401(d)(1)* employer, the government agency may file one Form 941 and/or one Form 940 for employment tax reporting purposes.

AUTHOR: Internal Revenue Service

GEOGRAPHIC: United States

REFERENCES: Subject Area:
Employment taxes;
Individual income taxation;
Information reporting

TEXT:

Release Date: AUGUST 06, 2003

Published by Tax Analysts™

UILC: 131.00-00, 3401.04-01

Release Date: 11/21/2003

Date: August 06, 2003

Refer Reply To: CC:TEGE:EOEG:ET1:PRENO-126058-02

Office of Chief Counsel
Internal Revenue Service Memorandum
Memorandum

To: Andrew Zuckerman, Acting Director
Federal State and Local Government T:GE:FSLG

From: Will E. McLeod
Chief, Employment Tax Branch 1 CC:TEGE:EOEG:ET1

Subject:
Taxability of Respite Care and *Section 3401(d)(1)* Reporting

[1] This Chief Counsel Advice responds to a memorandum from your predecessor dated April 30, 2002. In accordance with *Internal Revenue Code section 6110(k)(3)*, this Chief Counsel Advice should not be cited as precedent.

APPENDIX C

ISSUES

- (1) Whether respite care payments made to third parties for purposes of providing relief to foster care providers are excludable from gross income under *section 131*.
- (2) Whether a respite care provider is an independent contractor or a common law employee.
- (3) Whether the governmental agency that pays for the respite care is the *section 3401(d)* employer.
- (4) Whether the governmental agency, as the *section 3401(d)(1)* employer, may file one Form 941 and/or Form 940 for employment tax reporting purposes.

CONCLUSIONS

- (1) The payments made to respite care providers are not excludable from gross income under *section 131* because they do not meet the requirements of either *section 131(b)(1)(B)* or *section 131(b)(2)*.
- (2) To determine whether a respite care provider is an independent contractor or a common law employee of the agency providing remunerations to the respite care provider we need to analyze the facts and circumstances of the relationship between the respite care provider and the business. The facts are insufficient for us to make such a determination here.
- (3) If the governmental agency is not the common law employer of the respite care provider, the agency is the *section 3401(d)(1)* employer because the agency controls the payment of wages to the respite care provider.
- (4) The governmental agency as the *section 3401(d)(1)* employer, may file one Form 941 and/or one Form 940 for employment tax reporting purposes.

FACTS

- [2] Governmental entities that place individuals in foster care also pay for respite care. Respite care services are provided to the foster care providers in order for them to have relief from the responsibilities of being providers. Respite care allows the foster care provider to take a vacation or to have a few hours off from the responsibilities of providing foster care.
- [3] Most respite care providers are certified by the states as qualified foster care providers for qualified individuals. However, some respite care providers may not be

APPENDIX C

certified as a qualified foster care provider (e.g., relatives of the foster care provider). Also, some respite care providers perform services in their own home while others perform services in the homes of the foster care providers.

[4] Regardless of whether the respite care providers are certified, the government agencies make payments directly to the respite care providers. The governmental agencies, however, provide little direction to the respite care provider in the performance of their services.

[5] The foster care provider may request a specific respite provider to take care of the qualified foster care individual. Additionally, the foster care individual can request a specific respite care provider. Also, a respite care provider can refuse to provide services to either a specific foster care provider or refuse to care for a specific foster care individual based on length of stay or the circumstances of the foster care individual.

[6] In some states, the governmental agencies do not issue any reporting documents on the payment to respite care providers believing the payments fall under the definition of *section 131*. In other states, the payments are reported on either Form W-2 or Form 1099 MISC, under the assumption that these payments are taxable and not excludable under *section 131* because they are not payments made to the foster care provider.

LAW AND ANALYSIS

[7] Issue 1: Whether respite care payments made to third parties for purposes of providing relief to the foster care provider are excludable from gross income under *section 131*.

[8] *Section 131(a)* states that gross income shall not include amounts received by a foster care provider as qualified foster care payments. *Section 131(b)(1)* defines a qualified foster care payment as a payment made pursuant to a foster care program of a state or a political subdivision of a state: (A) that is paid by a state, a political subdivision of a state, or a qualified foster care placement agency; and (B) that is (i) paid to the foster care provider for caring for a qualified foster care individual in the foster care provider's home, or (ii) a difficulty of care payment.

[9] *Section 131(b)(2)* defines a qualified foster care individual as any individual who is living in a foster family home in which the individual was placed by an agency of a state, a political subdivision of a state, or a qualified foster care placement agency.

[10] *Section 131(b)(3)* defines a qualified foster care placement agency as any placement agency that is licensed or certified by a state or a political subdivision of a state, or an entity designated by a state or a political subdivision of a state for its foster care program to make foster care payments to providers of foster care.

APPENDIX C

[11] *Section 131(c)* defines a difficulty of care payment as a payment to an individual that is not described in *section 131(b)(1)(B)(i)* and that is compensation for providing the additional care of a qualified foster care individual that is required by reason of a physical, mental, or emotional handicap of the qualified foster care individual, if the state has determined a need for additional compensation because of the handicap, if the additional care is provided in the home of the foster care provider, and if the payment is designated by the payor as compensation for that purpose.

[12] We conclude that payments to respite care providers in the factual situations listed above are not excludable from gross income under *section 131* because the requirements of *section 131(b)(1)(B)* or *section 131(b)(2)* are not met. A governmental agency or qualified foster care placement agency does not place the individual in foster care with the respite care provider.

[13] *Section 131(b)(2)* requires a placement in foster care. It also requires that a governmental agency or a qualified foster care placement agency make the payment. The respite care is not provided in the respite care provider's home. See *section 131(b)(1)(B)*. The payment to the respite care provider is a payment for services and not a payment to cover the costs of care or a difficulty of care payment. See *section 131(b)(1)(B)*. These conclusions do not differ even if the respite care provider is certified as a foster care provider.

[14] Because the requirements of *section 131* are not satisfied, the payments received by the respite care provider are income under *section 61*. Thus, if the respite care provider is an independent contractor a Form 1099-MISC, Miscellaneous Income, should be issued to the provider for the payments received from the agency. On the other hand, if the respite care provider is a common law employee a Form W-2, Wage and Earnings Statement, should be furnished to the respite care provider.

[15] Issue 2: Whether a respite care provider is an independent contractor or a common law employee.

[16] For employment tax purposes, an employee includes an individual who, under the usual common law rules applicable in determining the employer-employee relationship, has the status of an employee. See *section 3121(d)(2)*; *section 3306(i)*; *section 31.3121(d)-1(c)(1)*; *section 31.3306(i)-1(a)*; and *31.3401(c)-1*.

[17] The employment tax regulations describe an employer- employee relationship:

Generally such relationship exists when the person for whom services are performed has the right to control and direct the individual who performs the services, not only as to the result to be accomplished by the work but also as to the details and means by which that result is accomplished. That is, an employee is subject to the will and control of the employer not only as to what shall be done but how it shall be done. In this connection, it is not necessary that the employer actually direct or control the manner in which the services are performed; it is sufficient if he has the right to do so. The

APPENDIX C

right to discharge is also an important factor indicating that the person possessing that right is an employer. Other factors characteristic of an employer . . . are the furnishing of tools and the furnishing of a place to work, to the individual who performs the services.

[18] Section 31.3121(d)-1(c)(2). See also, sections 31.3306(i)(b)-1(b) and 31.3401(c)-1(b).

[19] In determining whether an individual is an employee or an independent contractor under the common law, all evidence of control, and lack of control or autonomy must be considered. In doing so, one must examine the relationship of the worker and the business. Relevant facts generally fall into three categories: (1) behavioral controls, (2) financial controls, and (3) the relationship of the parties.

[20] Behavioral controls are evidenced by facts which illustrate whether the service recipient has a right to direct or control how the worker performs the specific tasks for which he or she is hired. Facts which illustrate whether there is a right to control how a worker performs a task include the provision of training or instruction.

[21] Financial controls are evidenced by facts which illustrate whether the service recipient has a right to direct or control the financial aspects of the worker's activities. These factors include whether a worker has made a significant investment, has unreimbursed expenses, and makes services available to the relevant market; the method of payment; and the opportunity for profit or loss.

[22] The relationship of the parties is generally evidenced by the parties' agreements and actions with respect to each other, including facts which show not only how they perceive their own relationship but also how they represent their relationship to others. Facts which illustrate how the parties perceive their relationship include the intent of the parties as expressed in written contracts, the provision of or lack of employee benefits, the right of the parties to terminate the relationship, the permanency of the relationship, and whether the services performed are part of the service recipient's regular business activities.

[23] *Rev. Rul. 56-502, 1956-2 C.B. 688*, involved individuals engaged by an agency to perform domestic services for its clients. *Rev. Rul. 56-502* stated that the agency is the employer of the individuals where the facts showed that: (1) the agency was engaged in the business of furnishing such services and so held itself out to the general public; (2) the agency furnishes the employment of the individuals and fixes their remuneration; (3) the clients for whom the services were performed looked to the agency for duly qualified and trained individuals; (4) the services were necessary to the conduct of the agency's business and promoted or advanced its business interests; and (5) the total business income of the agency was derived through a percentage of the remuneration received by the individuals for the performance of their services.

[24] In *Rev. Rul. 73-268, 1973-1C.B. 415*, workers were employed under separate contracts with a county to perform personal care and household management services

APPENDIX C

for disabled welfare recipients. The contract between the county welfare department and a worker provided homemaker services included a description of the workers duties, the minimum hours of service per month, the amount of remuneration, a statement that the homemaker assumed responsibility for work-related expenses, and that the worker would notify the department in the event he or she was unable to provide the contracted services. The contract could be terminated by either party by giving 30 days notice. However, the county could terminate the agreement at any time if the worker failed to meet his or her contractual obligations. The ruling concluded that the county exercised the degree of direction and control over the workers necessary to establish the relationship of employer and employee. Therefore, the workers were employees of the county.

[25] Because of the general nature of the factual situations you have presented, we are not able to provide you with a definitive answer as to whether respite care workers are employees or independent contractors.

[26] Issue 3: Whether the governmental agency that pays for the respite care is the *section 3401(d)* employer.

[27] If the governmental agency is not the common law employer of the respite care provider, the agency is considered to be the *section 3401(d)(1)* employer. *Section 3401(d)(1)* provides that the term "employer", for federal income tax withholding purposes means the person for whom an individual performs or performed any service, of whatever nature, as an employee of such person, except that, if the person for whom the individual performs or performed the services does not have control of the payment of wages for such services, the term "employer" means the person having control of the payment of such wages. *Regulation section 31.3401(d)-1(f)* provides that the term "employer" means the person having legal control of the payment of the wages. Since the governmental agency has legal control of the payment of the wages, the agency is the employer for purposes of *section 3401(a)* which defines "wages" as all remuneration for services performed by an employee for his or her employer.

[28] Neither the Federal Insurance Contributions Act (FICA) nor the Federal Unemployment Tax Act (FUTA) provisions contain a definition of employer similar to the definition contained in *section 3401(d)(1)*. However, *Otte v. United States*, 419 U.S. 43 (1974), holds that a person who is an employer under *section 3401(d)(1)* is also an employer for purposes of FICA withholding under *section 3102*. Circuit courts have applied the *Otte* holding to conclude that the person having control of the payment of the wages is also the employer for purposes of *section 3111*, which imposes FICA excise tax on employers and for purposes of *section 3301*, which imposes the FUTA tax on employers. See for example, *In re Armadillo Corp.*, 561 F.2d 1382 (10th Cir. 1977). Thus, the governmental agency is the employer for purposes of FICA, FUTA and income tax withholding.

[29] Issue 4: Whether the governmental agency, as the *section 3401(d)(1)* employer, may file one Form 941 and/or Form 940 for employment tax reporting purposes.

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[30] Pursuant to *Treas. Reg. section 31.6011(a)-1*, every employer must make a return for the first calendar quarter in which payment of wages is made subject to the tax imposed by the FICA. Form 941, Employer's Quarterly Federal Tax Return, is the form prescribed for making the return unless a composite return has been authorized by the Commissioner. Also, pursuant to section 31.6011(a)-3, every employer must make a return of tax under the FUTA for each calendar year. Form 940, Employer's Annual Federal Unemployment (FUTA) Tax Return, is the form prescribed for making the return unless use of a composite return as been authorized by the Commissioner. As the *section 3401(d)(1)* employer, the governmental agency may file one return for all of the employees of the agency.

[31] * * * *

[32] This writing may contain privileged information. Any unauthorized disclosure of this writing may have an adverse effect on privileges, such as the attorney client privilege. If disclosure becomes necessary, please contact this office for our views.

WILL E. MCLEOD

***** End of Document *****

Selected Resources

State Materials

GEORGIA

Georgia Department of Behavioral Health and Developmental Disabilities, "*Host /Life-Sharing Home Guidelines*," found at http://mhddad.dhr.georgia.gov/DHR-MHDDAD/DHR-MHDDAD_CommonFiles/Host%20LifeSharing%20Home%20Guidelines.pdf

MAINE

Maine Office of Adults with Cognitive and Physical Disability Services "*Shared Living Handbook*," Effective October 1, 2010, found at http://www.maine.gov/dhhs/OACPDS/DS/protocol-guidelines/shared_living.html

NEW YORK

New York: *Creating Innovative, Individualized Living Options For Persons with Developmental Disabilities: It's not about a model, it's about an approach*," New York State Association of Community and Residential Agencies, Prepared for: New York State Developmental Disabilities Planning Council, December, 2009.

PENNSYLVANIA

Pennsylvania Office of Developmental Programs, "*FY 2008-09 Lifesharing Through Family Living Directory Lifesharing Agency Survey Results*," PowerPoint Presentation, found at http://odpsrv.tiu11.org/alfresco/d/d/workspace/SpacesStore/dd889686-076a-4c40-9554-92ac2fed35c3/Lifesharing_Agency_Survey_Results_2008-2009.pdf

"*Lifesharing through Family Living*," (Mental Retardation Bulletin, Commonwealth Of Pennsylvania, Department Of Public Welfare, Number 00-05-04, Date of Issue August 8, 2005), <http://www.temple.edu/thetrainingpartnership/resources/mrBulletins/icf/00-05-04.pdf>

RHODE ISLAND

Rhode Island's description of shared living found at <http://www.mhrh.state.ri.us/about/pdf/sharedLiving.pdf>

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